

Between Two Worlds: A Qualitative Exploration of  
Language, Cultural and Other Barriers in Diabetes  
Consultations Involving Pakistani Patients.

**Naureen Ahmad**

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## **DECLARATION**

I hereby declare that

- i. This thesis has been composed by myself
- ii. The work presented within this thesis is my own unless otherwise stated
- iii. This work has not been submitted for any other degree or professional qualification.

Naureen Ahmad

2010

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## ABSTRACT

The **AIMS** of this study are to: (1) Explore the perceptions and experiences of diabetes consultations from the perspectives of Pakistani patients, health professionals and interpreters (when one was involved). (2) Identify the processes and mechanisms which hinder or foster effective communication between healthcare professionals and their patients. (3) Provide recommendations for ways in which communication can be improved between healthcare professionals and their Pakistani patients

**STUDY DESIGN:** A prospective qualitative study was developed, comprising three sequential components; namely: In-depth interviews with patients prior to a diabetes consultation; observation of the consultation; and, in-depth interviews with patients, health professionals and interpreters (when one was involved) following the consultation. Data were collected in the form of 10 detailed case studies. Each case study involved a Pakistani patient with type 2 diabetes mellitus (T2DM), their practitioner (s) involved in the consultation and an interpreter (if one was used).

**SAMPLE:** Five male and five female Pakistani with T2DM (aged 41-80 years), 12 practitioners (some patients consulted with two people) and three interpreters (two professional and one lay) were recruited through health services and personal contacts within Edinburgh's Pakistani community. Individual case studies were thematically analysed before all the case studies were compared/contrasted to identify cross-cutting themes.

**FINDINGS:** Alongside language, a range of barriers and issues were identified which impacted upon communication between patients and health professionals in the consultations observed.

Because of previous experiences of attending consultations in the UK and also in Pakistan, patients tended to come to their diabetes consultations with limited expectations; namely, to have their medication reviewed and receive test results. Consequently, patients tended not to raise health concerns and other issues unless they perceived these to be directly relevant to the consultation. In some cases, this resulted in patients not disclosing important information relating to their diabetes management and led to health professionals making inappropriate treatment recommendations.

The routine and predictable nature of these diabetes review consultations meant that patients could be passive, offer very little information and ‘get by’ in their consultations; for instance, by offering responses after guessing what the professional was asking. As a result, some health professionals were unaware of patients’ poor English and of how little they had understood during the consultation.

Health professionals found it difficult to establish understanding and rapport with patients who adopted a passive role in their consultations. This hindered them from identifying, and appropriately addressing, gaps in patients’ diabetes knowledge and any concerns they may have had.

Interpreters did not always address the language barrier and edited and misinterpreted information. This is partly because they struggled to interpret medical terminology. However, this research also revealed how interpreters can experience dilemmas and role conflicts by virtue of being members of the same closely-knit Pakistani community as the patients they interpret for.

Some of the barriers identified during this study also arose because patients tended to see different professionals at every visit which discouraged patient-provider relationships from being established.

**CONCLUSION:** Patients would benefit from receiving ‘continuity in care’ and education and training on how to use their consultations more effectively. Providers would also benefit from education and training on more effective ways to communicate with these patients.

# TABLE OF CONTENTS

<b>DECLARATION.....</b>	<b>i</b>
<b>ACKNOWLEDGEMENTS .....</b>	<b>ii</b>
<b>ABSTRACT .....</b>	<b>iii</b>
<b>CHAPTER ONE: INTRODUCTION.....</b>	<b>1</b>
1.1 Prologue: My Story .....	1
1.2 Diabetes in context .....	3
<b>CHAPTER TWO: THE PATIENT-PROVIDER RELATIONSHIP AND T2DM.....</b>	<b>11</b>
2.1 Introduction .....	11
2.2 The changing nature of healthcare.....	12
2.3 Parsons' concept of the 'sick role'.....	13
2.4 The changing nature of mortality and morbidity .....	16
2.5 What is chronic disease?.....	17
2.6 The Case of T2DM .....	17
2.6.1 The purpose of the diabetes consultation .....	19
2.6.2 Patient self-management .....	20
2.6.3 'Non-adherence' to self-management regimens.....	21
2.6.4 Personal, social and economic barriers to self-care .....	21
2.6.5 Lack of diabetes information and knowledge as a barrier to self-care.....	23
2.7 Compliance or adherence .....	24
2.8 Patient satisfaction.....	25
2.9 Patient-provider relationship – the two realms of thought .....	26
2.9.1 Patients' perspectives on illness.....	27
2.9.2 Implications of lay causal accounts.....	27
2.9.3 The health professional's perspective .....	28
2.10 The patient - provider relationship .....	29
2.11 Barriers to effective communication in the consultation.....	30
2.11.1 Healthcare professionals' communication styles .....	30
2.11.2 Patients' communicative styles .....	32
2.11.3 Conversational analysis/discourse analysis.....	33
2.11.4 Differing perceptions of the consultation.....	35
2.12 Is a 'patient- centred' approach the answer? .....	37
2.13 Summary.....	39

<b>CHAPTER THREE: CULTURE, LANGUAGE AND THE PATIENT-PROVIDER RELATIONSHIP .....</b>	<b>41</b>
3.1 Introduction .....	41
3.2 Disparities in health and healthcare .....	42
3.3 Access to, and uptake of, health care services.....	43
3.4 Culture and illness .....	44
3.5 Knowledge of diabetes in ethnic minority patients .....	46
3.6 South Asian Patients’ perceptions of UK health services.....	47
3.7 Individualism-collectivism construct.....	49
3.8 A Language barrier and interpreters as “solutions” .....	52
3.9 Summary.....	57
<b>CHAPTER FOUR: STUDY DESIGN.....</b>	<b>59</b>
4.1 Introduction .....	59
4.2 Theoretical stance .....	59
4.3 Observing the consultation .....	60
4.3.1 Participant observation.....	61
4.3.2 Non-participation observation.....	62
4.4 Qualitative Interviewing .....	63
4.4.1 Pre-consultation interviews with patients.....	64
4.4.2 Post-consultation interview with patients.....	65
4.4.3 Interviews with health professionals .....	66
4.4.4 Interviews with interpreters.....	67
4.5 Bringing the interviews together .....	68
4.6 Piloting consultation observations .....	69
4.6.1 Consultations with stakeholders.....	69
4.7 Study sample.....	70
4.8 Recruitment .....	71
4.8.1 Community recruitment .....	72
4.8.2 Health services recruitment.....	72
4.8.3 Recruitment of interpreters.....	77
4.9 Ethical considerations.....	77
4.10 Informed consent .....	78
4.11 Translating patient information material into Urdu .....	78
4.12 Assessment of patients’ English language skills .....	80
4.13 Transcription.....	81
4.14 Observing the actual consultations .....	81



4.14.1 Field notes while observing.....	82
4.14.2 What to observe in the consultation .....	83
4.14.3 Audio recording the consultation .....	84
4.14.4 Video or audio recording the consultation .....	84
4.15 Reactive effects.....	87
4.15.1 Digital audio-recorder .....	87
4.15.2 Researcher as observer .....	87
4.15.3 Interviewing participants.....	89
4.15.4 Building Rapport .....	90
4.16 The case study approach.....	91
4.16.1 What is a case study? .....	92
4.16.2 The case: A method or object of enquiry? .....	92
4.16.3 The purpose of the case study approach.....	94
4.16.4 Number of cases .....	94
4.17 Data Analysis.....	95
4.17.1 Analysis during data collection .....	96
4.17.2 Analysis after data collection .....	97
4.17.3 Within-Case Analysis.....	98
4.17.4 Cross-Case Analysis.....	98
<b>CHAPTER FIVE: CASE STUDY MR KHAN .....</b>	<b>101</b>
5.1 Introduction .....	101
5.2 Pre-consultation interview with Mr Khan .....	101
5.3 The consultation .....	106
5.3.1 Mr Khan's control of the consultation .....	113
5.4 Mr Khan's post-consultation interview .....	117
5.5 Interview with the doctor.....	120
5.6 Summary.....	124
<b>CHAPTER SIX: MR IBRAR AND MRS NARGIS.....</b>	<b>127</b>
6.1 Mr Ibrar.....	127
6.1.1 Pre-consultation interview.....	128
6.2 The consultation .....	131
6.3 Post-consultation interview with Mr Ibrar.....	136
6.4 The doctor's perception .....	140
6.5 Summary.....	143
6.6 Mrs Nargis .....	144
6.7 Mrs Nargis' Consultation .....	145

6.8 Mrs Nargis' post-consultation interview .....	149
6.9 Interview with GP.....	149
6.10 Summary.....	151
<b>CHAPTER SEVEN: MR SHABIR .....</b>	<b>153</b>
7.1 Mr Shabir's story .....	153
7.2 The consultation .....	158
7.3 The interpreter's view.....	166
7.4 Post-consultation interview with Mr Shabir .....	170
7.5 The doctor's view .....	174
7.6 Summary.....	177
<b>CHAPTER EIGHT: MR RAZA AND MRS SALMA.....</b>	<b>179</b>
8.1 Mr Raza .....	179
8.1.1 Pre-consultation interview with Mr Raza.....	180
8.2 Mr Raza's interpreter .....	183
8.3 The consultation .....	184
8.3.1 Creating spaces and gaps.....	188
8.3.2 Making and breaking off eye contact.....	189
8.4 Other non-language barriers .....	190
8.5 Mrs Salma.....	191
8.5.1 Pre-consultation interview.....	192
8.6 Mrs Salma's interpreter .....	193
8.7 In the waiting room.....	193
8.8 Messages arising from the consultation.....	197
8.9 Post-consultation interview with Mrs Salma .....	199
8.10 Patient's views about their interpreters.....	201
8.11 Interpreters' perceptions of their roles.....	201
8.11.1 The 'involved' interpreter .....	201
8.11.2 The 'impartial' interpreter.....	204
8.11.3 The interpreter who offered his guidance.....	206
8.12 Health professionals' perceptions of Mr Raza's interpreter .....	208
8.13 Health professionals' perceptions of Mrs Salma's interpreter.....	209
8.14 Summary.....	211
<b>CHAPTER NINE: FROM CASE STUDIES TO CROSS-CUTTING THEMES.....</b>	<b>213</b>
9.1 Introduction .....	213
9.2 Summary of key findings.....	213
9.2.1 Language Barrier.....	213

9.2.2 Limited and narrow communication .....	214
9.2.3 Patients' undisclosed health concerns .....	215
9.2.4 Passive patients .....	216
9.2.5 what constitutes as successful communication?.....	217
9.2.6 Interpreter Involvement.....	219
9.2.7 Providers' views about their patients .....	220
9.2.8 Providers' approach in the consultation .....	221
<b>CHAPTER TEN: DISCUSSION .....</b>	<b>223</b>
10.1 Introduction .....	223
10.2 Is 'effective' communication happening?.....	223
10.3 A language barrier – is it an over-problematised issue? .....	224
10.4 Undisclosed agendas.....	226
10.5 Lack of continuity discourages patients' agendas from being voiced .....	228
10.6 Unvoiced agendas as a strategy to manage a language barrier.....	230
10.7 Passive 'control' .....	231
10.8 Impression management .....	233
10.9 Negative stereotyping .....	235
10.10 Providers' 'controlling' communication.....	237
10.11 Structural and organisational constraints.....	239
10.12 Do interpreters 'improve' communication between patients and their providers? .....	240
10.13 Interpreters as a resource for help and advice.....	242
10.14 Methodological reflections .....	243
10.14.1 My position as a Pakistani Muslim researcher .....	244
10.14.2 Narrative reconstruction .....	246
10.14.3 Methodological strengths .....	246
10.14.4 Methodological limitations .....	247
10.15 Policy and practice recommendations .....	249
10.15.1 Educate patients to make better use of their consultations.....	249
10.15.2 Provide continuity of care .....	250
10.15.3 Educating providers.....	251
10.15.4 Recording and reviewing patients' medication .....	252
10.15.5 Improving triadic consultations.....	253
10.16 The direction of existing policy and the relevance of this study .....	254
10.17 Recommendations for future research .....	256
10.18 Conclusion .....	257
<b>REFERENCES.....</b>	<b>259</b>

<b>APPENDICES .....</b>	<b>279</b>
Appendix 1a - Interview Schedule for Patients interview before consultation.....	279
Appendix 1b - Interview Schedule for Patients interview after consultation .....	281
Appendix 1c - Interview Schedule for Health Professionals .....	284
Appendix 1d - Interview Schedule for Interpreters .....	286
Appendix 2a - Patient Invitation Letter .....	288
Appendix 2b - Patient Information sheet.....	289
Appendix 3a - Health Professional Invitation Letter for use in General Practice/Community Recruitment .....	291
Appendix 3b - Health Professional Information Sheet for use in General Practice .....	292
Appendix 4a - Professional Interpreter Invitation Letter.....	293
Appendix 4b - Professional Interpreter Information Sheet.....	294
Appendix 5 – Patient Consent Form.....	295
Appendix 6 - Patient opt in form .....	296

# CHAPTER ONE: INTRODUCTION

## 1.1 Prologue: My Story

To begin, I feel it would be useful to set the context for this study and explain how the idea for this thesis arose, and how my personal and professional experiences influenced this doctoral studentship.

I am an Edinburgh-born British Pakistani, born to parents who migrated to the UK in the 1960s. My parents, who were married in Pakistan, came from a conservative background and, like many other migrant Pakistanis of that era, ran ‘corner-shop’ businesses in the UK. These businesses were successful, and were therefore an incentive for them to remain in the UK. At the age of 11, my parents sent me to live and study in Pakistan, partly to help enhance my understanding of Pakistani/Islamic cultural and religious values; while also readying me for a possible future life in Pakistan should they have decided to return ‘home’. I lived there for two years, during which time I gained a unique insight into the cultural and religious traditions that govern ‘everyday living’ in Pakistan. Since my family had strong kinship ties with their relatives in Pakistan, they strengthened these ties by inviting relatives to come to the UK and stay with us, often for several months at a time. Like many other Pakistanis living in the UK, my parents also tried to strengthen ties and preserve their traditional cultural values by marrying three of their children, including me, to our cousins in Pakistan. This resulted in a cohort of ‘second- generation’ or a younger group of the first generation Pakistanis settling in the UK.

Since I can speak and understand English and Punjabi, I was (and still am) often asked to accompany my mother, visiting relatives and, more commonly, my sisters-in-law, and my then husband, to their medical appointments. In these consultations I acted as an interpreter, a cultural mediator, and was an on-going source of advice for these people outside their consultations. Enacting these roles sometimes caused me to become frustrated as my relatives would ask me to make decisions on their behalf, and for my opinion regarding the doctor’s advice/recommendations. Subsequently, if a treatment did not work then I would be held accountable because I had ‘endorsed’ the doctor’s advice.

In my experience as an interpreter, I also found myself offering explanations to my relatives about the cultural differences they experienced when attending appointments. One example

was when I had to explain *why* GPs were the gatekeepers to specialist services, and how, unlike in Pakistan, patients in the UK needed to be referred instead of simply turning up to see a specialist. Conversely, during consultations I rarely raised any issues about cultural differences with health professionals, partly because of time-pressures, but also because I was never certain how relevant the health professionals would consider this information to be to the task in hand. For example, once I accompanied my aunt who had recently arrived from Pakistan, to a medical appointment, as she was having some heart problems. She was seen by a male doctor who asked her, via me, to remove her top and bra to allow him to carry out an examination. I was aware of the insensitivity of this request in the context of Pakistani Muslim norms, but instead of explaining to the doctor why this might be awkward for my aunt, I told my aunt that the doctor needed to examine her. She asked me how I felt about this and I said that the doctor was ‘doing his job’ and, taking my advice, she decided to go ahead with the examination. In truth, this was an awkward situation for both me and my aunt; however, it demonstrates some of the dilemmas I experienced. On one hand, I wanted to be seen as being co-operative with healthcare professionals and, on the other, I wanted my relatives to receive a comprehensive consultation so that their problems were identified and treated effectively.

Naturally, then, I had a vested interest in understanding more about health and communication-related matters involving Pakistanis who had limited English language skills. I took up voluntary work with an agency that offered advocacy help to people with mental illness and, as part of that, had the opportunity to interpret and advocate for South Asian clients in Edinburgh, whose first language was not English. After that, a post for a bi-lingual research associate came up at the University of Edinburgh, presenting an opportunity to conduct qualitative research with Indians and Pakistanis living in Edinburgh. This research involved exploring their views and experiences of diabetes service provision in Lothian through in-depth interviews. Working on this study motivated and informed my decision to pursue this PhD research, as it drew my attention to a lack of research insight into the consultation interaction between South Asian patients and their providers in the context of diabetes care. For instance, most respondents on this earlier study reported a high level of ‘satisfaction’ with their diabetes consultations but, as the study progressed, it became clear from their accounts that patients had a poor understanding of their disease and, were struggling to control it effectively in the context of their everyday lives.

I was privileged to have worked with Dr Julia Lawton, the principal investigator on this earlier study. Dr Lawton recognised the value of my language skills, background and relevant personal experiences and, together, we made an application for this studentship to the Chief Scientist Office (Edinburgh) with me as a named applicant. Professor Amanda Amos, another highly-regarded scholar, agreed to co-supervise me together with Dr Lawton. I was mentored, intellectually challenged and nurtured by Dr Lawton and Prof. Amos and they will always remain a source of inspiration to me. It was worth noting here that, as part of my commitment to this PhD research, I learnt to speak and write Urdu fluently in the first year of this research. This was invaluable, particularly, when I had to translate written materials from English into Urdu. After providing some insight into how I came to do this doctoral research, I will now explain why, in a public health context, this particular piece of research is both important and timely.

In my own experience, diabetes has affected the majority of the Pakistani families I have known in Edinburgh. My mother was diagnosed with diabetes 15 years ago and all of her generation of friends now also have the condition. Many of these people are on insulin therapy and/or are suffering from the complications of this disease. Diabetes is so common among the Edinburgh Pakistani community that, before I joined the University as a research associate, I, like some other Pakistanis, did not consider diabetes to be a preventable or manageable condition, assuming that diabetes was a disease the vast majority of people would at some point develop.

## **1.2 Diabetes in context**

Type 2 diabetes mellitus (which will be referred to as T2DM hereafter in this thesis) is a cause of serious long-term health complications with significant morbidity (Zimmet, 2003). Its prevalence is increasing rapidly in the UK, presenting the NHS with serious clinical and financial challenges (Bagust, 2008). The onus is placed upon the individual to manage this complex disease through tight glucose and blood pressure control, as well as adherence to lifestyle advice and, as the disease progresses people tend to move onto tablets (oral glucose lowering agents) and insulin. Many people with diabetes struggle to follow their diabetic regimens, and commitment to self-management may decrease over time (Funnell and Anderson, 2004).

Diabetes is at least four times more common among British South Asians than in the general population (Barnett et al. 2006). It is worth noting here that the term 'South Asian' being

used here refers to UK residents with ancestral origins in the Indian Subcontinent, and includes Pakistanis, Bangladeshis and Indians as they comprise the largest South Asian groups in the UK. However, South Asians are not a homogenous group and many differences, including those arising from religion and culture, exist between them. In this thesis, however the term 'South Asian' will be used as it is the one which is widely used in academic and health service research literature, notwithstanding its limitations. Mortality associated with T2DM is also significantly higher in South Asians, due in part to their blood glucose and pressure control being poorer and more erratic than among their White counterparts (D'Costa et al. 2000). Poor levels of diabetes knowledge amongst South Asian patients have been highlighted as a particular cause for concern (Perez-Stable et al. 1994). Many South Asian people with diabetes know less than their White counterparts about diabetic risk factors and complications, as well as the importance of blood glucose monitoring and control (Baradaran and Knill-Jones, 2004; Hawthorne, 1990; 1994). Poor diabetes knowledge has been attributed to educational and linguistic barriers experienced by British South Asians (Hawthorne, 1994). Most first generation South Asians receive less formal education than the White population, the majority do not speak English as a first language, and many speak little or no English (Greenhalgh, 1997).

The consultation process is the key tool used by healthcare professionals to provide diabetes education to patients, make decisions about treatment, and motivate self-care (Parkin and Skinner, 2003). However, research has shown that there may be significant disagreement between patients and health professionals about the purpose and outcomes of consultations (Parkin and Skinner, 2003), and what they consider to be the main clinical, educational and psychosocial issues and outcomes (Woodcock and Kinmonth, 2001). This research has focused on patients who speak English as a first language, and who often share the same class and educational backgrounds as their health professionals. At present, we know little about the logistics and additional challenges created by consultations where both language and cultural barriers may exist between patients and health professionals; and, third parties may be required to interpret. However, the limited evidence available indicates that, when interpreters are used, not only is mistranslation and editing of information common, but they may also bring their own agendas and values to bear in the interpretation process (Hsieh, 2006; 2007). Other work suggests that South Asian patients have unrealistic expectations of the patient-practitioner relationship which may also lead to misunderstandings in the consultation context (Rosenberg et al. 2007a; Hawthorne, 1994). I will further explore these issues in a later chapter.



It is now well established that patients' motivation for diabetes management improves when they can communicate effectively with health professionals, and identify common goals and objectives (Pooley et al. 2001). It has also been predicted that South Asian patients' demands for diabetes services will increase substantially over the next few decades because of the growing prevalence of the disease, and also due to this being an ageing population and the increased risk of diabetes as people age (Barnett et al. 2006). Arguably, both factors make the proposed area of investigation timely and important. For the purposes of this research, consultations with only Pakistani patients were investigated, as this is the largest minority population in Scotland (Scotland Census, 2001), also it is appropriate to have focussed on only one ethnic group in this small study due to heterogeneity between (and within) ethnic groups. Furthermore, since I am Pakistani I had a vested interest in doing research in a community within which I belonged.

The aims of this study were to:

- Explore the perceptions and experiences of diabetes consultations from the perspectives of Pakistani patients, health care professionals and interpreters (when one was involved).
- Identify the processes and mechanisms which hinder or foster effective communication between healthcare professionals and their patients
- Provide recommendations for ways in which communication can be improved between healthcare professionals and their Pakistani patients.

I will now briefly outline each of chapters that will follow in this thesis.

In Chapter Two, the first of two chapters in which the literature relevant to this study is reviewed, I begin by reflecting on the patient-provider relationship as described by Parsons (1951) and his concept of the 'sick-role'. I will then describe some of ways in which healthcare delivery has changed and how these changes have shaped, or at least challenged, the traditional structure of the doctor-patient relationship. I then proceed to give an understanding of some of the issues and debates surrounding the patient-provider relationship in the context of chronic illness. I will show that, irrespective of a language and/or cultural difference, some barriers to effective communication may exist in most consultations, thus it is important to identify these issues to avoid stereotyping and assigning these 'widespread problems' to consultations involving ethnic minority patients. In

justifying my decision to focus upon the case of T2DM, some important contextual and background information will be given about the disease, including the risk factors that contribute to it and its complications. I will describe some of the difficulties and challenges that this disease has posed both to the individual, in terms of personal barriers to self-management, and to healthcare services, in relation to patients' poor adherence to treatment regimens.

In the final section of this chapter, I will describe how the 'patient-centred' and 'shared decision-making' models, have been proposed to improve the patient-provider relationship with a view that these models will help to empower patients to better manage their condition. However, as I will describe, these models have not been widely implemented and, indeed, not all patients want to take on the role of 'active' participant in their consultations.

In Chapter Three I describe and discuss the literature which examines the consultation interaction involving patients who belong to ethnic minority groups. Using the previous chapter as a comparison point, this chapter will describe the literature which has looked at the specific challenges and difficulties arising in cross-cultural consultations. In such consultations, patients and providers may experience challenges, in addition to the ones described in chapter two, that arise because of cultural and/or language differences. I will briefly describe how some cultural differences that might impact upon the patient-provider relationship and patients' disease self-management, may be explained in terms of the individualistic/collectivist values that people in different cultures may hold. In addition, I will describe some of the inequalities in health and healthcare that exist for ethnic minority patients, especially those with T2DM, and ways these affect UK South Asians more than the White population. Also, I will explore why South Asian patients with T2DM have poorer levels of diabetes knowledge than their White counterparts.

In this chapter, I will also draw upon the literature regarding consultations that involve an interpreter. Hsieh's (2006; 2007) work, as I will show, is particularly useful in providing some insight into the challenges and difficulties that professional interpreters may experience since they are often managing dual roles. Interpreters, as I will show, may experience role conflicts which make it difficult for them to be objective and impartial during these consultations. Finally I will look at some of the dilemmas and issues that arise when patients were accompanied by lay (family/friend) interpreters.

In Chapter Four, I will describe the qualitative case-study research design used in this study which allowed exploration of communication issues in cross-cultural consultations. I will argue that one of the benefits of this research design is that it made it possible to highlight, understand, and explore, discrepancies between what people said they have done, or will do, and what they actually did or will do in the context of their consultations. I explain why I chose to conduct in-depth interviews and non-participant observation of consultations and how this research design was both resource- and labour-intensive. In addition, I describe some of the challenges and dilemmas that I faced both during my interviews (particularly with patients) and also whilst observing the consultations. This chapter also includes details of the two-pronged recruitment strategy used which included health services and community-based recruitment. I will also reflect on some of my personal experiences of conducting research within a Pakistani community to which I belonged.

Chapter Five describes in detail a complete case study in order to provide an illustration of the rich data and depth of insight I was able to access, by using my multi-method design. This case study involved Mr Khan who spoke very limited English and, is used as a starting point to explore how a language barrier can affect communication between a patient and a provider. It is also used to set the scene for exploration of other themes that began to emerge from this example, and which are taken forwards in the following analysis chapters. Some of the issues that emerged included Mr Khan's positive perception of the consultation experience despite it being riddled with miscommunication and, involving a break down in conversation between him and his doctor. I also show, amongst other things, how the doctor held stereotypical assumptions about Mr Khan which may have affected how he communicated with him.

In Chapter Six, two case studies involving Mr Ibrar and Mrs Nargis are described. Both patients had better spoken English than Mr Khan enabling comparison of different language skills and the effect of these on patient-provider communication. In this chapter I illustrate that even when patients spoke better English than Mr Khan, other barriers hindered effective communication between patients and their providers. In this chapter I will tease out those communication issues which are related to a language difference, and those issues which may be common to consultations irrespective of a language and cultural difference. One of these barriers as I will show was patients' passive behaviours during their consultations which their doctors reported as being problematic as they were uncertain about how much of what they said was understood by these patients.

In Chapter Seven, I present a case study involving Mr Shabir who was accompanied to his consultation by a professional interpreter. I do this in order to highlight some of the difficulties that can take place in triadic consultations. Mr Shabir's interpreter was professional, yet as I will show this did not promote effective communication between him and his doctor. Hence, Mr Shabir's case study is used to highlight how interpreter support may not alleviate, but rather add to the existing barriers. The complexities of patient-interpreter relationships outside the consultation setting, as I will go on to show, help to shed light on some of the decisions that interpreters may make during the consultation.

In Chapter Eight, I describe two case studies involving interpreters, in order to take forward some of the findings that arose from the case study involving Mr Shabir. In the first case study I illustrate a case study involving Mr Raza who, like Mr Shabir, was accompanied by a professional interpreter. I will show how this interpreter had a different translating style to Mr Shabir's interpreter and how these 'interpreter differences' might affect the quality of communication between patients and their providers. The second case study involving Mrs Salma who was accompanied by a lay interpreter, is used to illustrate how the patient-interpreter relationship outside the consultation setting can affect what goes on during the consultation interaction. Taking forward my observation in the previous chapter I will suggest that, by virtue of serving a close-knit Pakistani community, these interpreters were often faced with dilemmas which force them to make choices and difficult decisions. Implicit in these choices and decisions is how they view themselves in relation to the community in which they belong.

In the penultimate Chapter (Nine), I summarise the key findings that arose from the six case studies described in the previous four findings chapters which are most salient to the aims of this thesis. In doing this, I will also briefly draw upon findings from the remaining four case studies that have not been described in the previous chapters, in order to illustrate and reinforce the ways in which key findings reported in this thesis cut across the dataset. Whereas in previous chapters I presented whole case studies in order to illustrate my findings and analysis, in this chapter, I summarise and synthesise the key cross-cutting themes across some or all of the case studies.

The Final Chapter Ten comprises four sections. First, I discuss how the empirical findings arising from this thesis can be interpreted in light of the existing literature and current theoretical insights into cross-cultural consultations. Second, I describe some of the

methodological strengths and limitations of this study. I then use the findings from this study to provide some policy and practice recommendations for improving the quality of diabetes consultations involving Pakistani, and possibly other ethnic minority, patients. Finally, I provide some recommendations for further research.



## CHAPTER TWO: THE PATIENT-PROVIDER RELATIONSHIP AND T2DM

### 2.1 Introduction

In this chapter I will present an overview of the issues and debates surrounding the patient-provider relationship in the context of chronic illness, in particular, T2DM. This is a common condition which typifies many of the generic problems associated with chronic illness. I will describe some of the difficulties and challenges that this disease has posed in terms of:

- Barriers to self-management for the individual
- Challenges to the health care services in relation to patients' poor treatment adherence
- Other barriers to diabetes self-management which may be personal, material or structural.

Finally, I will explain how the quality of the consultation interaction has been seen to influence patients' adherence to self- management strategies in the context of chronic illness. I will argue how the lack of concordance between lay explanatory models and the biomedical model may have implications for the patient-provider relationship, and as an illustration, I will draw upon how lay and biomedical understandings of disease causation may conflict which can pose some challenges for the delivery of healthcare.

My research is concerned with exploring communication in diabetes consultations involving Pakistan patients and, it is important that I first highlight what is already known about consultation interactions involving patients and providers who share the same first language and, cultural backgrounds. This is because the *problematic* nature of the patient-provider relationship may partly be explained by issues which cut across consultations irrespective of any language and cultural differences between the consulting parties. In the following chapter, I will make comparisons between the main themes arising from this chapter and, the consultation literature that has specifically explored language barriers and cultural differences between patients and health care professionals. I will do this in order to identify the specific problems that may arise out of there being language and cultural differences between patients and their healthcare professionals.

I begin the chapter by describing some of the ways in which healthcare delivery has changed since the early 20<sup>th</sup> century, and how these changes have impacted upon the patient-provider relationship. The work of Parsons, (1951) an influential sociologist, will be used as a starting point for illustrating how some of the key debates in medical sociology have changed and developed over time. I will describe and explore how the increase in the cases of chronic illnesses, has prompted many studies which have looked at the (in) effectiveness of the traditional consultation style for the (self) management of chronic illnesses. I will then describe the specific reasons which have been identified in the literature as contributing to ineffective communication between patients and their providers, including patients' and health professionals' consulting styles.

Finally, I will briefly describe how 'patient-centred' care and shared-decision making have been proposed as solutions to some of the problems in communication between patients and their providers. However, I will argue that these models have seldom been implemented as they are not clearly linked to immediate health gains, and they are restricted by the current structure of the consultations. Despite, the changes to healthcare delivery that have taken place over the past decades, it appears that the patient-provider relationship has still retained some of its traditional characteristics.

## **2.2 The changing nature of healthcare**

Since the early 20<sup>th</sup> century healthcare delivery has undergone vast changes. In tandem with the shift from 'bedside medicine' (Armstrong, 2005) in the 18<sup>th</sup> century to a more institutionalised and organised form of healthcare known as 'hospital medicine', the roles of the doctor and the patient have also changed, reflecting the rising dominance and authority of the medical institution (Engel, 1978). Instead of doctors being invited into the patient's home to offer their services, with the advent of hospital medicine, patients were expected to visit hospitals if they required medical assistance (Hulka et al. 1975). With this shift, the way in which doctors performed their consultations changed radically. No longer were doctors seen to be hand-holding and nurturing, taking patients' emotional state into consideration and basing their medical decisions solely on the accounts of symptoms provided by patients in their 'beds'. Instead, with the advent of medical procedures and the introduction of the 'clinical examination' (Foucault, 1963), doctors were able to diagnose patients without relying on patients' subjective accounts. More credibility was assigned to diagnosis that was supposedly achieved by identifying and investigating the 'pathological lesion' which caused the signs and symptoms of the disease. In this way, doctors became



increasingly detached from the 'illness experience' which was considered unquantifiable and therefore 'unscientific' (Armstrong, 1985).

Foucault (1963) described these shifts in healthcare delivery as a shift in the structures of knowledge which, according to him, promoted certain power interests. The material and intellectual structures that made possible the analysis of the body, fashioned the idea of a mind-body dualism in which the body could be manipulated as an objective entity. Foucault referred to this as the objectifying 'medical gaze', whereby the practitioner and the wider healthcare institution separated the affective and socio-emotional dimension of disease from the pathological lesion in the host body. Practitioners as 'experts' of the human body garnered authority over the 'passive' patient and thereby wider power in society, setting in place the hierarchical structure of the medical institution.

Medical authority and dominance grew and expanded without seemingly much resistance from other knowledge-based disciplines until the mid 20<sup>th</sup> century. Most writings on the history of the medical institution and, more specifically the doctor-patient relationship, include reference to the work of American sociologist Talcott Parsons. Parsons (1951) analysed the structure of the doctor-patient interaction and the function it played in wider society. Although Parsons' analysis can be seen as a defence, and an explanation, of the structure and function of this social system, his work was seminal in that he was the first person to examine the broader implications of the doctor's and the patient's roles. Parsons' work generated wide and critical interest in the doctor-patient relationship which according to some people gave rise to research disciplines such as medical sociology (Strauss, 1957).

### **2.3 Parsons' concept of the 'sick role'**

Parsons (1951), a structuralist-functionalist, described how the doctor-patient relationship was important to the functioning of society. His work, which was less concerned with communication between the doctor and patient, transcended the specificities of the actual interaction. Parsons' focus was upon the *structural* and *functional* aspects of what he termed the 'sick role'. In his view, a sick person entered into a role of 'sanctioned deviance' because he/she was in most cases temporarily too unwell to perform as a productive member of society. Parsons claimed that doctors' and patients' roles were socially prescribed, so that they performed functions in line with expectations imposed by the medical institution. Doctors had the authority to decide which patients would be ascribed the temporary social role of being sick and it was the doctor's responsibility to then return these sick people to a

state of health and restore them to being fully functioning members of society as quickly as possible. In this way, doctors, as Parsons argued, were agents of social control in their role as gatekeepers to the 'sick role'.

Parsons himself recognised that the nature of the doctor-patient relationship reflects a paternalistic set-up, in which the doctor is the decision making expert, and the patient the passive recipient of his/her 'expertise'. He argued that this hierarchy was inevitable as the doctor was the one with the professional expertise and knowledge to diagnose and treat a patient's illness. The patient's position on other hand was to seek out this specialist expertise and 'to get well' by permitting the doctor to restore his or her health by whatever means was thought appropriate by the doctor. Theoretically, then, the patient was in a position of 'inferiority' and lacked the resources to challenge or contest the doctor's medical action. However, recently historical changes such as consumerism, which promote patient empowerment, have meant that the asymmetrical but 'functionally appropriate' balance of power recognised by Parsons had started to be questioned.

Indeed, Parsons' work has been widely criticised by health and social researchers who argue that his concept of the sick role is outdated and does not account for the chronic disease burden that has enveloped modern society [Segall, 1976; Levine and Kozloff, 1978; Radley, 1994]. Parsons' concept was formulated and principally applies to the acute illness situation, one in which the patient will either recover or die, so exemption from social duties is afforded (Radley, 1994). However, patients suffering from chronic illness are not afforded similar exemptions, because their illness is long-term or permanent and being 'off sick' for the duration of it would not be financially feasible or indeed socially acceptable. Thus these patients are expected to manage their illness whilst carrying on with their daily duties and performing their social responsibilities (Radley, 1994).

Crossley (1998) has critiqued the relevance of Parsons' concept of the 'sick role' in contemporary society, by arguing that Parsons' work was highly influenced by the cultural and historical contexts in which his work arose. For instance, Crossley states that Parsons' concept of social responsibility was tied up with ideas about rights and obligations in the workplace, which were largely shaped by a Western Protestant work ethic, based on the premise that hard work and worldly success is a means of personal salvation. Hence, it is not surprising that one of the exemptions Parsons associated with the 'sick role' was the 'legitimate' relief from the responsibilities of work. However, Parsons surmised that certain

conditions had to be met by the patient in order to pass as 'sick' and, thus be granted these exemptions.

Parsons' concept also received criticism because of the way patient's roles were represented in relation to the doctor's role. Parsons' argued that, in order for the functions of the relationship to be successful, patients must be compliant, co-operative, dependant and passive. Levine and Kozloff (1978) argue that by discounting patient agency, the authority of the patient is underplayed and the medical authority of the doctor exaggerated. Also implicit in Parsons' work is the assumption that medicine works for the good of society as a whole (Crossley, 1998) when, arguably, it is a way of promoting certain power interests (Foucault, 1963).

Parsons foresaw that his work may be subject to criticisms given that the prevalence of chronic illnesses was rising and, in 1975, attempted to defend some of the claims that he had made (Parsons, 1975). Parsons addressed the critique that the 'sick role' is inapplicable to people suffering from chronic illness by arguing that this concept was concerned with the sustainability of people's roles in society as a whole regardless of the type of illness. He explained that, whereas in the case of acute illness the goal is to cure the patient; in the case of chronic illness it is about averting further deterioration by proper medically prescribed measures based on a formal diagnosis. Parsons referred to the case of diabetes and, how good dietary control and adherence to oral or injected medication can maintain 'physiological functioning' which, in turn, enables individuals to resume and sustain 'normal' activities. Thus, the individual suffering from chronic illness does not require exemption from his/her social duties and obligations as long as they comply with the doctor's medical advice and prevent health deterioration. It appears that Parsons' response to his critics does not extend beyond his view of the functions of the consultation and nowhere does he actually acknowledge how the chronically ill patient is required to implement and maintain complex self-management outwith the doctor-patient structure.

The other critique Parsons addressed was to do with his model of the asymmetric role relationship between the doctor and the patient which rendered the latter passive. Parsons argues that patients lack professional medical competence, compared to the health professional, thus the relationship will always remain asymmetrical, regardless of personal experience and exposure to disease. This kind of competence is characterised by medical and technical knowledge, and skills founded on formal training and experience.

Although Parsons mapped out a coherent view of the practice and structure of medicine, his work emerged at a time when the authoritative nature of the medical establishment was rapidly gaining 'power', and there was a relatively high incidence of acute illness. Since Parsons originally formulated his ideas, society and the prevalence of chronic illness has changed but nonetheless Parsons' work serves as a useful starting point for illustrating how some of the key debates in medical sociology have since developed, some of which are particularly relevant to this thesis. It is the doctor's limited healing ability with regards to chronic illness which has exposed weaknesses in the traditional structure and function of the doctor-patient relationship (Frosch and Kaplan, 1999). Not only are doctors unable to cure the patient with chronic illness but they can no longer always act as 'gatekeepers' to the sick role as, unlike with acute diseases, patients with a chronic condition never stop being 'sick'.

Parsons' work also sets the stage for further discussion relating to the asymmetrical nature of the doctor-patient relationship. The impact of medical authority and professional dominance has become increasingly evident in studies concerned with patients' adherence to therapeutic treatments and, those which have explored the illness experience from patients' perspectives. Simultaneously, this has resulted in a critical interrogation of the legitimacy and competency of the medical profession (Phillips, 1996). Furthermore, broader trends in society, which I will describe below, have reduced the autonomy and monopoly of the medical profession. Thus, the changing nature of illness, together with an emerging critique, mainly from healthcare studies and medical sociology/anthropology disciplines, of the medical profession sets the context for the current state of the doctor-patient relationship as I will now go on to describe in more detail.

## **2.4 The changing nature of mortality and morbidity**

The prevalence of chronic illness has risen considerably in most western countries due to two related, but separate, accomplishments of medicine (Gerhardt, 1990). Firstly, there has been a reduction in certain infectious diseases, such as pneumonia and tuberculosis, which were the most frequent causes of death of the chronically ill until the 1940s. Secondly, the dramatic improvement in drug treatments (such as antibiotics, chemotherapy and insulin) as well as surgical intervention, has improved the life expectancy of people with chronic illness (Gerhardt, 1990). Additionally, social and economic changes such as industrialisation, better housing, and improved sanitation have reduced mortality rates amongst Western populations as a whole (Scambler, 1997). The prevalence of chronic illness is rapidly increasing for two reasons: firstly, people are now living long enough, for the reasons

mentioned above, to develop them; and, secondly lifestyle changes are commonplace, such as poor diet and lack of physical activity which are seen as 'risk factors' for obesity and some chronic diseases such as T2DM, heart disease and stroke (Field et al.. 2001; Strong et al. 2005). In the next section, I will discuss the nature and effects of chronic illness upon individuals and healthcare.

## **2.5 What is chronic disease?**

Rheumatoid arthritis, coronary heart disease, stroke, diabetes, HIV, AIDS and certain forms of cancer are common examples of chronic disease. The fundamental characteristics of most chronic diseases are that they are often permanent, progressive and can be debilitating (Charmaz, 1983). Chronic disease can oscillate between periods of acute and mild symptoms (Kleinman, 1988). Some chronic diseases are ultimately fatal, while others can be stabilised with an effective management regimen (Scambler, 1997). Some of the problems encountered by people with a chronic disease stem directly from the symptomatic nature of their illness (Bury, 1988). Individuals with the same diagnosed disease can experience different symptoms, for instance, a person with diabetes may, typically, experience a loss of sensation in their feet, while another person may not suffer from this symptom. In other respects, the problems faced by people with chronic disease may be common to all, irrespective of the nature of their condition. Individuals experience unemployment, or reduced career prospects, social isolation, estrangement from family and friends, loss of important roles, changed physical appearance and problems with self-esteem and identity (Ohman et al. 2003; Kleinman, 1988; Scambler, 1997; Charmaz, 1983).

In this thesis, I have specifically chosen to focus upon patients with T2DM as it is a common condition that typifies many of the generic 'problems' associated with chronic disease. As I describe below, these problems may relate to the: patient-provider encounter; patients' self-management strategies and patients' 'non-adherence' to therapeutic treatment. T2DM also poses a considerable public health challenge in contemporary society and, is particularly prevalent in the British South Asian population (McKeigue, 1991).

## **2.6 The Case of T2DM**

According to the prevailing biomedical view, T2DM is a chronic, multi-factorial disorder characterised by elevated blood glucose levels resulting from an absolute or relative lack of the hormone insulin (Davies et al. 2004; Fox and MacKinnon, 2002). T2DM differs from

type 1 diabetes as in the case of Type 1 diabetes, the body produces very little or no insulin at all, cases usually occurs at a younger age compared with T2DM; and patients with this condition are in need of insulin therapy as soon as they are diagnosed (Fox and MacKinnon, 2002).

T2DM, on the other hand, is usually common in middle-aged or older people and does not always need insulin therapy to keep it under control. T2DM is potentially a very serious condition, with those diagnosed being at an increased risk of developing macro- and micro-vascular complications such as heart attacks and strokes and complications of the nervous system (Fox and Mackinnon 2002; Guillausseau, 2005). Not only does the condition cause substantial morbidity, it can also reduce life expectancy by up to fifteen years (Davies et al. 2004). T2DM can have a profound effect on quality of life if it is not managed properly (Funnell et al. 2004; Vermeire et al. 2003; Callaghan and Williams, 1994). With good management, complications can be delayed, but not altogether halted, as T2DM is a progressive condition and deterioration is often inevitable (UKPDS, 1998). Nevertheless, lifestyle improvement, such as dietary management and increased physical activity, is encouraged to reduce the risk complications and to improve the quality of life (Wolpert & Anderson, 2001). Some patients are required to take tablets/insulin as part of their management programme, to maintain or improve their blood glucose control (Fox and Mackinnon, 2002).

The biomedically recognised causes of T2DM are multi-factorial. Some of the main risk factors are: age, poor diet, sedentary lifestyles which leads to obesity, and a genetic predisposition (Eriksson and Lindgarde, 1991). Obesity is considered a major risk factor for T2DM, and recently it has also been recognised that psychological stress may play a part in the aetiology and management of diabetes (Wales, 1995). T2DM is currently incurable thus medical interventions are directed towards the control of diabetes-related symptoms and complications by enhancing glycaemic control (Van Dulmen et al. 1997).

T2DM constitutes a major public health problem (Narayan et al. 2000). The global explosion in diabetes has meant it has received a high profile within biomedical, public health and social science forums (Peel et al. 2007). According to the 1998 WHO report, diabetes cases in adults will more than double globally from 143 million in 1997 to 300 million in 2025 as a result of population growth, ageing and lifestyle changes as described above. Bagust et al. (2002) claim that, in the next 30 years, T2DM will present a serious

clinical and financial challenge to the National Health Services in the UK. In the UK there are about 1.3 million people diagnosed with diabetes, costing about five percent of NHS resources, and about £802 a year in healthcare costs plus lost earnings to each affected individual (Department of Health, 2001). A National Service Framework for Diabetes (NSFD) was published by the Department of Health in 2001 and sets out the first ever set of national standards for the care of people with diabetes. The NSFD was established to improve services by setting national standards to drive up service quality and tackle variations in care. The standards set by the NSFD identify the interventions and actions that will help meet those standards and the milestones against which NHS performance will be measured. Standard four of the NSFD states that:

*“All adults with diabetes will receive high-quality care throughout their lifetime, including support to optimise the control of their blood glucose, blood pressure and other risk factors for developing the complications of diabetes.”* (NSFD standards; p.5)

This care is primarily delivered through the diabetes consultation, which I will now go on to describe.

### **2.6.1 The purpose of the diabetes consultation**

Under these current standards and guidelines set out by the NSFD, patients with diabetes must receive regular, at least annually, diabetes review appointments. These appointments involve a consultation with a health professional with diabetes training/expertise. Review appointments are either carried out in the hospital with a consultant or as is progressively the case due to the devolvement of diabetes services to primary care in the UK, they are being undertaken in a diabetes clinic within the general practice setting which is led/overseen by a lead GP for diabetes or a lead nurse with diabetes training. As part of these consultations, patients HbA1c (Haemoglobin A1c), the amount of glycated haemoglobin in the blood is monitored, which is considered the gold standard for the assessment of glycaemic control in diabetes. Also, their cholesterol levels are checked as high levels in patients with diabetes can increase the risk of arteriosclerosis. A patient's blood pressure is measured because high blood pressure is related to the development of heart disease, kidney and eye damage. Other examinations, such as foot checks to assess nerve sensitivity and retinopathy of the eyes may be undertaken during these review appointments. Indeed it is a requirement of the Framework that these foot and eye checks are done annually.

While sophisticated tests and technologies may be used for medical diagnosis and treatment, the consultation remains the primary tool by which the healthcare professional and the patient exchange diabetes-related information (Parkin and Skinner, 2003). From a health service perspective, the purpose of these consultations is to: 1) monitor patients' diabetes control through a series of tests (described above) and examinations (of the feet and sometimes eyes); 2) review patients' current medicinal treatment plan and re-assess in light of test/examinations results and blood glucose self-monitoring diary if patients who are on insulin are required to fill one; 3) provide lifestyle advice (mainly on exercise and diet) and information on the complications associated with diabetes and 4) ask patients to raise and discuss any problems they may be having.

Through strategies that seek to empower patients it is hoped that these consultations will have a positive effect lasting beyond the consultation setting. By motivating patients and providing them with information and education, healthcare professionals may enable them to take control of, and effectively manage, their illness (Maclean and Goldman, 2000). They may do this by seeking to: influence the choices these patients make in their daily lives (Ciechanowski et al. 2001); persuade patients that they can be in control of these choices (Woodcock and Kinmonth, 2001); and, remind patients that their choices can either have positive or negative consequences for their health. Thus, the overall aim of these consultations is to help and encourage patients improve their metabolic control by promoting adherence through a patient-centred approach (Fox and Mackinnon, 2002).

### **2.6.2 Patient self-management**

While the onset of long-term complications can be delayed and immediate symptoms controlled through good metabolic control, medical intervention can only do so much in the management of T2DM (Engel, 1989). It is essentially the patient's responsibility to keep their blood glucose levels as close to normal levels as possible. Heavy emphasis is also placed on controlling other risk factors, such as blood pressure and cholesterol (Fox and Mackinnon, 2002). People with T2DM are often advised to make changes to their daily practices, involving their diet and physical activity levels (Hernandez, 1995). Patients who are over-weight are commonly advised to lose weight as this can improve metabolic control. Alongside managing the risk factors which can lead to complications, patients are responsible for monitoring their condition and ensuring that they adhere to any medical treatments prescribed by their doctor.



### **2.6.3 'Non-adherence' to self-management regimens**

A serious problem in the management of chronic illness is the low level of adherence to the treatment regimens that are prescribed and/or recommended by healthcare professionals (Glasgow et al. 1987; Bloom, 2001). Diabetes treatment regimens are complex and challenging and may require significant lifestyle and behavioural changes. It is commonly reported that patients struggle to incorporate these changes in the face of other competing factors, such as family commitments, employment and financial issues, combined with a lack of understanding about their condition (Nagelkerk et al. 2006; Ohman et al. 2003).

Many reasons are provided in the literature for why patients may have poor self-management and find it difficult to adhere to therapeutic advice and recommendations. Within this literature, two inter-related issues/areas can be traced. The first is concerned with the personal challenges and difficulties confronted by patients. Qualitative research in this area has explored patients' experiences of living with and managing their chronic illness in the context of their everyday lives. This work has shown that personal, social and economic barriers can stand in the way of successful disease self-management. The second is concerned with the ways in which the nature and the quality of patients' interactions with healthcare professionals can impact upon their adherence to medical advice. In the following sections I will briefly describe some of the personal and social barriers to self-care before examining the patient-provider relationship in detail.

### **2.6.4 Personal, social and economic barriers to self-care**

Callaghan and Williams (1994), in a study which explored patients' perceptions of living with diabetes (both Type 1 and 2), described the process of managing diabetes, as a conscious effort on the part of the patient to take over what is normally an automatic and unseen physiological process of blood sugar regulation. The complex, multi-faceted and often challenging regimens of self-control is carried out with a concern for the consequences of blood sugar imbalance. This balance is delicate and tension exists between keeping blood sugar in the normal range and therefore risking hypoglycaemia and keeping blood sugar higher than normal thus risking long-term complications. Respondents, in this study, were reported to recognise the impact of diabetes on their lives yet, most of them reported that they continued to function in a normal way by controlling how 'invasive' and 'restricted' their diabetes was allowed to become. Callaghan and Williams (1994) refer to this as the 'normalising process', whereby patients perceived their diabetes as merely an 'irritation' or

‘an inconvenience’ or a ‘way of life. It is not just about keeping the diabetes in balance but also fitting it in and juggling it with other competing priorities and demands in one’s life without letting it become the main priority.

Barriers to self-care arise when there is a conflict between the requirements of disease management and obligations to other concerns in a person’s life. These barriers can be external, such as the lack of access to facilities in which to undertake physical activity, lack of money to buy “healthy” foods, and barriers to do with the healthcare systems (Nagelkerk et al. 2006). Internal barriers can be related to the physical effects of treatment and can be social and/or psychological, such as domestic and employment responsibilities which may restrict the possibility of leading a healthy and active lifestyle (Lutfey and Wishner, 1999). Those struggling to make ends meet may not be as concerned about adherence as they are about their personal financial issues. Indeed, leading a healthy lifestyle, which can involve acquiring, a gym membership, home exercise equipment and choosing quality but often pricey foods, can be costly in itself. Other priorities that may compete with the actions required to manage one’s illness are the demands and pressures of a family (Fisher et al. 1998). Women who are primarily in charge of domestic household chores may face barriers different to those experienced by men. Pressures of managing mealtime and trying to fit in with the rest of the family who may not consume a diabetes-friendly diet, or eat at the times a patient may have to, to follow their regimen can be counterproductive to blood glucose management (Peel et al. 2007). Forgetting to take pills/insulin and the side-effects of treatment can also discourage patients from properly managing their condition (Lawton et al. 2008). Social stigma (Wens et al. 2005), the embarrassment of injecting insulin due to the lack of privacy, poor motivation and personal and cultural health beliefs and attitudes towards lifestyle choices may contribute to poor adherence (Simmons, 2001; Vermeire et al. 2003; Wens et al. 2005; Lutfey and Wishner, 1999). Some patients experience helplessness and frustration arising from poor glycaemic control and continued disease progression despite adherence (Nagelkerk et al. 2006), this poor control may negatively affect their self-efficacy and hinder further self-care (Peel et al. 2007; Glasgow et al. 2001). Loss of spontaneity and the constant need to accommodate the illness when planning activities makes it difficult to maintain control (Callaghan and Williams, 1994). Literacy levels have also been associated with poorer diabetes knowledge and self-care (Powell et al. 2007). Even those individuals who successfully manage their diabetes take ‘breaks’ from the monotony of self-care routines by reducing self-monitoring and straying from the prescribed diet (Peel et al. 2007; Paterson et al. 1998). The asymptomatic nature of diabetes in some

cases can deceive people into thinking their condition is well controlled, causing them to 'slack' in their self-care regimens (Simmons, 2001).

As some of the literature reviewed above indicates patients' perceptions of their disease can also mediate or hinder their self-management behaviours. How serious patients perceived their diabetes to be may have implications for the time and effort they invest in their self-care (Campbell et al. 2003). Approaches to management may range from the 'relaxed' to the 'vigilant' (Callaghan and Williams, 1994). Eborall et al. (2007) found in their study that newly diagnosed patients, particularly those on a diet-only regimen talked confidently about their plans to control their disease, as the exclusion of pills/insulin fuelled their perception that they had a milder and therefore more manageable form of diabetes.

### **2.6.5 Lack of diabetes information and knowledge as a barrier to self-care**

A lack of diabetes knowledge and information has repeatedly been reported as giving rise to poor-self care (Knight et al. 2006; Pooley et al.2001). For people with T2DM, information is a significant resource for managing this complex chronic disease. Such knowledge includes understanding the patho-physiology of diabetes and the rationale for adherence to medical advice (Paterson et al. 1998). Basic knowledge of diabetes is an important prerequisite for appropriate disease management as it may reduce uncertainty, help the individual to come to terms with the illness and allow for the development of strategies for managing the illness in everyday life (Ciechanowski et al. 2001; Maclean and Goldman, 2000; Van Dulmen et al. 1997). Simmons (2002) advises that knowledge itself does not necessarily create an ability to enhance self-care, especially if other priorities and barriers exist but it is considered a necessary pre-requisite. Nevertheless, many people with chronic conditions express dissatisfaction with the amount of information they are able to obtain about their illness and the limited input they have into decisions about their treatment (Ciechanowski et al. 2001; Scambler, 1997; Ong et al. 1995; Thorne and Robinson, 1988).

So far, I have briefly discussed some of the barriers to effective self-care with which patients are confronted in their everyday lives. I have described how patients who are not always equipped with adequate diabetes knowledge may find it difficult to manage and control their diabetes as a consequence. Patients may acquire diabetes knowledge from a variety of sources, including friends/relatives who have diabetes, media and the internet. Patients may also be given the opportunity to attend a 'Structured Education Programme', but this opportunity only tends to arise early on in their disease. These programmes such as

DESMOND (Diabetes Education and Self Management for ongoing and Newly Diagnosed) are tailored for the newly diagnosed (Skinner et al.2006). One of the main channels through which information/knowledge is meant to be delivered to patients is the diabetes consultation and this is also the arena in which treatment decisions are made. However, it has been shown that barriers to effective communication exist between health professionals and patients with chronic illness, which may be affecting the successful delivery of this information/education. Before I describe some of these barriers, I will briefly comment on some concepts/definitions that tend to be used in the consultation literature as there is some controversy surrounding the use of particular terms which first needs to be acknowledged.

## **2.7 Compliance or adherence**

The terms ‘compliance’ and ‘adherence’ are often used interchangeably in the consultation and patient satisfaction literature with the latter term, currently, being the preferred one. Until recently, the term ‘non-compliant’ was used to label patients who ‘failed’ to implement effective self-care strategies resulting in poor disease control. For example, Hulka et al. (1975) refer to studies conducted in the 1960’s which have branded patients as ‘non-compliant’ on the premise that patients’ medicine-taking behaviours did not conform with the medication prescribed in their medical records. In another study by Hulka et al. (1976) the degree of patient ‘compliance’ was measured against appointments kept and the appropriate use of prescription drugs.

Lutfey and Wishner (1999) have called for the term ‘compliance’ to be reconceptualised in terms of ‘adherence’. The authors argue that the term ‘compliance’ locates the source of non-compliant behaviour with the patient and suggests that the way to solve non-compliance is by changing patient behaviour. Adherence, on the other hand, is considered a less accusatory concept which has been conceptually expanded to consider social circumstances, in addition to various psychological barriers, as causes of non-adherence (Lutfey, 2005). However, Lutfey (2005) argue that the literature using this term still conceives non-adherence as an ‘individual-level phenomenon’ based on factors and barriers situated in patients’ lives rather than related to healthcare professionals’ role. It still implies that medical advice should be adhered to rather than the advice itself being problematic (Lutfey, 2005). Even though ‘adherence’ still appears to be an undecided term I will use it in this thesis because it is a term commonly used in the literature on diabetes management.

## 2.8 Patient satisfaction

Patient 'satisfaction' is another concept which as I will argue in this thesis, is problematic. The last two decades have seen an upsurge in academic and health service research studies on the measurement of patient satisfaction and the strength of its association with treatment adherence. The rationale for patient satisfaction measures appears to be two-fold. Firstly, researchers argue that patients who are 'satisfied' with the care they receive are more likely to adhere to therapeutic regimens and, secondly, patient satisfaction measures can be used as an evaluative tool to measure how well health services are performing. Quantitative methods, such as opinion surveys and 'satisfaction' questionnaires, have been the primary tool by which such information is gathered and performances gauged (Ross et al. 1995; Ware and Hays, 1988; Linn and Greenfield, 1982). These research tools generate data in the form of 'fixed' responses to pre-defined questions and hypothesis. LeBow (1983) listed the results of over 50 surveys which measured patient satisfaction and calculated that the average percentage of satisfied patients was 77.5 per cent. Avis et al. (1997) argue that these measures and, indeed, the concept of 'satisfaction' fail to capture the problematic nature of health service delivery to patients and provide misleading 'evidence'.

A similar contention is made by Williams (1994) who argues that the use of the term 'satisfaction' denotes some sort of fixed state that exists amongst healthcare users which can be accessed and measured using survey based methods. Williams (1994) argues that patient satisfaction measures are too narrow and exclude a plethora of personal, social and contextual factors which may influence and impact upon a patient's perceived usefulness of these services. Furthermore, expressions of satisfaction are circumstantial and dependent on factors such as the severity of the illness, any associated pain experienced by the sufferer and, whether the prognosis is bleak or hopeful (Williams, 1994). In the context of the consultation interaction, these data may not be particularly informative as satisfaction measures appear to generate data suggesting that most patients are satisfied most of the time (Sitzia, 1997; Meredith, 1993). The results of such surveys also contradict studies (Barry et al. 2000; Street, 1992) which have identified the patient-provider interaction to be problematic. Patient satisfaction surveys may not capture what actually occurs during the patient-provider interactions, and may also be biased towards representing the patients' views. In the methods chapter of this thesis I will expand on this point and discuss how the research design for this study will overcome some of the limitations that have been experienced in using patient satisfaction surveys.

## **2.9 Patient-provider relationship – the two realms of thought**

Returning to the reasons why patients with chronic illness may find it difficult to adhere to their self-care regimens, I have so far described some personal, circumstantial, economical and psychological barriers that may promote poor adherence. Looking specifically at the literature on consultation interaction, however, it also becomes evident that problems may arise from the conflict between providers' own values and those of some of their patients. Specifically, there may be a distinction between lay and biomedical understandings of health, disease and illness which is referred to as the two realms of thought in the context of the patient-provider relationship. In other words patients and providers may hold disparate views about symptoms, signs, medication and treatment etc. Firstly I will describe why the patient-provider relationship has been problematic and what the implications of this are upon patients' treatment adherence.

It has been argued that biomedicine's preoccupation with disease and its dissociation from the patient's illness experience (Barry et al. 2001) are partly responsible for patient non-adherence, patient dissatisfaction with healthcare and inadequate or inappropriate clinical care delivery (May et al. 2004; Hunt and Arar, 2001 and Phillips, 1996). Although there are several components to healthcare, the consultation interaction tends to be where discrepancies between patients' and providers' perspectives become most apparent. The consulting style of the provider has been called into question as a consequence (Engel, 1978) and how this may hinder the patient's illness experience from being recognised, acknowledged and managed in these interactions.

Sociological studies from the 1980s onwards have paid much attention to the differences between lay and professional understandings of disease and illness, with researchers challenging the epistemological nature of biomedicine and arguing that lay explanations of health and illness are no less logical or complex than those of medical professionals (Blaxter, 1997). Kleinman's (1988) work is seminal in providing a rich and nuanced account of the meaning of illness and its subjective experience in the context of everyday living. He described the distress and the daily problems associated with living with a chronic illness and the patient's judgement and ability to best cope with them. He understood disease to be the language of doctors and, in essence, a clinical view which reduces the patient's illness experience to a chronology of symptoms and signs. Kleinman (1988) described how illness experience is idiosyncratic, context-bound and culturally shaped and is central to the decisions patients make about illness behaviour. The underlying assertion is that, individuals

whose explanatory models and disease understandings conflict with, or diverge from, the biomedical model, are less likely to adhere to medical instructions (May et al. 2004; Hunt and Arar, 2001 and Phillips, 1996; Cohen et al. 1994 ).

Studies which have looked at lay and biomedical understandings of health, disease and illness can be separated into two groups: those that explore how and why the lay paradigms differ from providers' paradigms of disease and those that explore how this difference may impact upon the communication process in the consultation interaction. I will firstly and briefly look at the former before examining the latter in more detail.

### **2.9.1 Patients' perspectives on illness**

How individuals make sense of an illness has been a major focus of enquiry in the health and social sciences. The eliciting of the patient's perspective is considered a way of understanding the psychosocial effects, emotional consequences and practical difficulties of coping with an illness. To this end, 'lay explanatory models' (Blaxter, 1997; Cohen et al. 1994), 'illness narratives' (Kleinman, 1988) and the 'insiders' perspective' (Gerhardt, 1990) amongst other similar terms have been proposed as ways to conceptualise and represent the lived experience of illness through the patient's eyes. The concept of 'lay expertise' has gained currency as a way of describing the process by which the patient gains intellectual, psychological and physical mastery over their illness, thereby enabling themselves to better cope with it (Bissell et al. 2004). An example of how discrepancies between patient and providers explanatory models can have implications for patient's disease-management can be found in lay accounts and biomedical understandings of disease causation.

### **2.9.2 Implications of lay causal accounts**

Arguably, lay causal accounts can be used to predict an individual's likelihood to accept responsibility for the management of their illness. For instance, Schoenberg et al. (1998) evaluated the relationship between causal explanations of diabetes and adherence to dietary recommendations and found that respondents who linked the onset of their diabetes to their dietary practices and weight gain were more likely to follow dietary advice given by health professionals. Also, Thompson and Gifford (2000) found in their interview study involving Aborigines with T 2DM that those who assigned the cause of their illness to factors over which they perceived themselves to have little or no control reported that they were less likely to adhere to self-management practices. However, Pill and Stott (1982) argue that

these conclusions suggests a rather simplistic and formulaic relationship between disease causation and an individual's self-management practices and, in their study, involving working-class women, found that whilst patients' causation explanations could be predicted using their levels of education, these could not always be used to predict patients' perceptions about the impact of their illness and, their ideas around self-management. While patients' illness causation accounts may, provide an indication of patients' likelihood to adhere to self-management strategies, Thompson and Gifford (2000) argue that problems related to 'non-adherence' may also arise because of health professionals focus on bio-medical strategies to promote adherence in patients.

### **2.9.3 The health professional's perspective**

In the literature health professionals' views are typically represented as narrow, reductionist and medically defined. Their concern is with the physical manifestation of disease and not with the social, emotional and situational contexts of the illness experience (Hunt and Arar, 2001; Barry et al. 2001; Phillips, 1996; Engel, 1989; Strong, 1979). Particularly, in the case of diabetes, the health professional's goal is to encourage patients to adhere to their treatment advice so that they can sustain normal blood glucose control. The rationale for good self-care is presented as something which will minimise the severity of complications and improves quality of life. However, the matter is more complex than this. Loewe et al. (1998) conducted an interview study to elicit doctors' narratives in the context of diabetes and found that doctors were pessimistic about the prognosis of their patients who were suffering from diabetes. Doctors acknowledged their doubts about the benefits of glycaemic control or even the possibility of weight loss in some patients; yet they often ended up blaming their patients for poor adherence or negative outcomes. Similarly, in another study by Larme and Pugh (1998) who interviewed primary care providers in the US also found that health professionals were frustrated as prognosis was unpredictable, but they also felt that they received mixed messages about how to treat diabetic patients which added to their uncertainty over whether they were actually helping to delay future complications in their patients. The point to be made here is that health professionals' explanations of disease management may be technically complex and dissimilar to the ways in which patients view their illness but, like patients, they may develop their own unique perspectives based on their personal and common experiences.

There are limitations to drawing upon patients' and providers explanatory models, and how these may conflict, because they do not tell us enough about the conflicts that arise directly



out of the patient-provider interaction. Specifically, explanatory models do not tell us enough about interactions, but more what is going on outside of these actual interactions. The emphasis on belief systems, essentially limits the study of the patient-provider interaction to a meaning-centred approach. It focuses mainly on the health and illness beliefs of individuals and not on the doctor-patient interaction itself (Lazarus, 1988). An almost exclusive concentration on eliciting and interpreting patients' explanatory model forces the study away from a critical evaluation of the healthcare professional's own role in the interaction and therefore away from the healthcare professional's responsibility (Heritage and Maynard, 2006).

In the following section, I specifically focus on studies that have examined patient-provider interaction in the context of the consultation. Some researchers have directly observed the consultation while others have relied on patients' and health professionals' retrospective accounts of their consultation experiences. I will provide an overview of those factors which have so far been identified as 'problematic' in these encounters. Although I endeavour to refer specifically to those studies concerned with diabetes, where relevant, studies involving patients with other chronic conditions are included to elaborate particular points.

## **2.10 The patient - provider relationship**

Being a multifaceted and multidimensional phenomenon, the doctor-patient relationship is one of the most complex inter-personal relationships (Ong, 1995) and therefore an especially difficult topic for research. Generally speaking, there are three different purposes to communication between healthcare professionals and patients which are: 1) creating an inter-personal relationship; 2) exchange of information; and, 3) diagnosis and making treatment related decisions (Heritage and Maynard, 2006; Ong et al. 1995; Roter and Hall, 1989). Studies, however, have shown that patients with T2DM are not following an optimum management regimen partly because, as mentioned earlier, poor communication exists between providers and patients (Pooley et al. 2001; Woodcock and Kinmonth, 2001; Elwyn et al. 1999; Van Dulmen et al. 1997; Street, 1992). Whilst, in the literature, it is frequently argued that the doctor-patient interaction is problematic, in relation to these claims relatively few researchers, as I will go on to show, have actually studied the specific communication patterns and features which are creating these 'problematic' consultations.

## **2.11 Barriers to effective communication in the consultation**

Broadly speaking the following ‘problem’ areas have been identified as contributing to poor communication between healthcare professionals and their patients including: healthcare professionals’ communication styles; patients’ communication styles; dissimilar patient-provider perceptions; healthcare professionals’ and patients’ characteristics; and, structural barriers and constraints. I will briefly expand on and describe some of the issues that relate to each problem area that has been identified in the literature. This is important as it will, in part, provide a justification for my choice of methods used in the current study.

### **2.11.1 Healthcare professionals’ communication styles**

The way healthcare professionals communicate with their patients has been the subject of much attention in healthcare related literature. It is generally agreed that those healthcare professionals who exert ‘control’ in consultations and take on a dominant, paternalistic role may inadvertently generate counter-productive results (including non-adherence) and contribute to poorer health outcome in patients (Street et al. 1993). This is because providers who ‘control’ the consultation may make it difficult for patients to raise their concerns and problems which may result in problems being unaddressed (Waitzkin, 1984).

Studies which have looked directly at consultations (Ong et al. 1995; Roter and Hall, 1989) have suggested that providers’ communication behaviours can be separated into two main dimensions: the instrumental dimension and the affective dimension. The former (also referred to as cure-orientated or task-related) involves providing information and advice to patients, eliciting medically-related information from patients, performing medical examinations and problem-solving. The latter includes behaviour which: is rapport-building (e.g. the degree of friendliness; showing concern and empathy); and, is emotionally supportive.

Generally, it is reported that healthcare professionals who tend to display a high degree of instrumental rather than affective dimensions in their communication behaviours can contribute to patient dissatisfaction and non-adherence (Williams et al. 1998; Bensing, 1991). However, Ong et al. (1995) argue that this may be a false and simplistic dichotomy because the two dimensions can be inter-changeable and are largely dependent on how patients perceive their provider’s communicative behaviours. For instance, although information-giving in itself is not an affective behaviour, it may fulfil an emotionally

supportive function for the patient. Also, instrumental behaviour can take on affective significance through the way it is conveyed (e.g. provider's tone of voice). Providers may also maintain 'high control' during the consultations by asking patients closed instead of open questions and by initiating most of the questions (Roter et al. 1988). Another way that providers may exert control in consultations is if they use complex medical and technical terms without explaining their meaning to patients. Ong et al. (1995) describe doctors as being bi-lingual because they speak both the 'everyday language' (which is concordant with patients' language) and are also fluent in the 'medical language'. The authors stress that communication is hindered when providers talk in the medical language as patients may feel out of their depth and, become non-communicative.

Non-verbal communication in consultations can also be a barrier to effective communication in consultations. Friedman (1979) explains why patients are sensitive and observant of non-verbal communications conveyed by their practitioners. Illness usually involves emotions such as fear, anxiety and emotional uncertainty and thus patients will look for subtle cues to find out what they ought to be thinking and feeling. Non-verbal communication concerns the manner of communication not its content. Specific non-verbal cues can convey affect, empathy, interest and caring (Ruusuvuori, 2001) but can also create feelings of frustration (if patients feel doctors are rushing them) and neglect in patients (Roter and Hall, 1989). Non-verbal behaviours are thought to convey the socio-emotional tone of the interpersonal interaction (Ong et al. 1995) and include features such as providers' tone of voice, direction of gaze, posture, laughter, facial expressions, touch and physical distance (Ruusuvuori, 2001; Van Dulmen et al. 1997; Ong et al. 1995). This literature has highlighted the importance of exploring the non-verbal as well as verbal dimensions of communication between patients and their providers (Thus as will be described later in chapter four, the research design for this thesis included an observational component, in part, to look at the non-verbal aspects to the patient-provider communication and whether it hindered or facilitated communication).

Evidence suggests that patient characteristics such as their gender, age, education, social class, ethnicity and prognosis may have an influence on the way health professionals communicate with them (Barry et al. 2001; Ong et al. 1995; Street et al. 1993). In their observational study involving patients with T2DM, Street et al. (1993) found that educated patients engaged in more decision-making behaviours and that control of the consultation was more equally distributed between these patients and their health professionals. Patients

with limited education tend to be passive and deferent in their consultation and thus tend to receive less information from their providers (Arora and McHorney, 2000).

While healthcare professionals' communication styles and behaviours have been scrutinised and problematised, the same level of attention has not been directed towards patients' communicative behaviours. Instead patients' self-reported experiences of the encounter and their preferences have tended to be described. Much less attention has been devoted to understanding problematising patient behaviour within the medical encounter through direct observation. In the following section I will describe aspects of patients' consulting styles which may impact upon the quality of communication in consultations.

### **2.11.2 Patients' communicative styles**

Studies have shown that patients who are more active during their consultations in terms of asking questions, expressing opinions, raising topics of concern and who express more positive and negative emotion are more likely to understand treatment rationales and recommendations than patients who display a passive demeanour (Harrington et al. 2004; Williams et al. 1998). A growing body of evidence suggests that verbally active patients are more 'satisfied' (Street and Buller, 1988) but it is less clear whether they may experience improved medical outcomes (Harrington et al. 2004; Greenfield et al. 1988).

While studies have found that a patient's active participation in consultations is heavily influenced by the degree to which they are educated, age has also been linked with the degree to which they actively participate in their consultations. For instance, McKinstry (2000) who interviewed patients in Lothian, Scotland using video vignettes of acted consultations, which displayed either the 'shared' or 'directive' approach, found that, in the main, older patients preferred the directive approach. When asked why, these patients explained that their role was to be passive recipients of care and that this was the style they had always been used to. As McKinstry contends, older patients are part of a generation who saw the doctor as a traditional power figure and someone to be revered and obeyed. Therefore, older patients may not be ready to play a more active role because they are sceptical about what is new or unfamiliar and their views may simply be reflecting a desire to maintain the status quo (McKinstry, 2000).

Studies in which patients' pre-consultation accounts have been compared to video or audio-recordings of the consultation have found that patients' concerns may remain unaddressed in

consultations where patients talk very little. For instance, Barry et al. (2000), who interviewed patients before and after their consultations, found in their interviews with patients attending general practice appointments that often patients had several and diverse agendas including concerns about their symptoms, illness fears, and emotional and social issues that they wanted to air in their prospective consultation. However, patients often did not raise their agendas or concerns and, even when patients' agendas were biomedically orientated, such as reporting side-effect problems with drugs, the researchers found in their consultation observations that patients sometimes refrained from raising these with their healthcare professionals. The authors observed that some of these 'unvoiced agendas' led to specific problem outcomes; for example, major misunderstandings, unwanted prescriptions, non-use of prescriptions, and non-adherence to treatment. One reason they gave for patients not expressing all their agendas was that something which may have seemed important to the patient before their consultation may seem less so during their consultation. Nevertheless, if patients are selecting information/issues to raise in their consultations, then there is a risk that important and potentially relevant information will be missed.

Here, we can begin to see that patient's consulting styles may be affected by several different factors. As described earlier, health professionals may be 'controlling' during these interactions and may adapt their communication styles according to how they perceive the patient. Patients' styles or behaviours during the consultation may also dictate the nature of the interaction with their providers. To help understand how communication in consultations is enacted, conversation and/or discourse analysis can be applied to the 'talk' element in the interaction. In this thesis's findings chapters some of the technical terminology used in conversation analysis will be drawn upon to help enhance our understanding of some of the dynamics of the patient-provider communication.

### **2.11.3 Conversational analysis/discourse analysis**

The focus of discourse analysis is any form of written or spoken language, such as a conversation or a newspaper article (Brinton et al. 1995). The main topic of interest is the underlying social structures, which may be assumed or played out within the conversation or text. Studies of discourse have been carried out within a variety of traditions that investigate the relations between language, structure and agency. It concerns the sorts of tools and strategies people use when engaged in communication, such as slowing one's speech for emphasis, use of metaphors, choice of particular words to display affect, and so on (Brinton et al. 1995).

Conversational analysis (commonly abbreviated to CA) is the study of talk in interaction in an every day situation such as in the patient-provider interaction (Atkinson, 1995). In terms of conversational data, the researcher uses the transcript of the conversation (a systematic way of coding the words) as their source (Goodwin and Heritage, 1990). A detailed transcription of a video- or audio- recorded conversation is produced in which every utterance is recorded including the silent pauses. The conversation is then subject to analysis which seeks to identify patterns and occurrences that occur in the course of the conversation. An example might be mother-child conversations focussing on situations that provoke anxiety, or more relevant- a conversation between a patient and their healthcare professional about the patient's symptoms.

The set of patterns that govern conversations include *turn-taking*. Turn-taking is one of the fundamental organisations of conversation which is regarded as universal to all conversations in any language (Atkinson, 1995). It is a process by which interactants allocate the right or obligation to participate in an interactional activity. The turn allocational component allocates turns among participants in a conversation. The three ordered options are: Current Speaker selects Next Speaker; Next Speaker Self-selects as Next; or Current Speaker Continues (Atkinson, 1995).

Repair organisation describes how parties in conversation deal with problems in speaking, hearing or understanding. It is the mechanisms through which certain "troubles" in interaction are dealt with. Repair is classified by who initiates repair (self or other) and by who resolves the problem (self or other) as well as by how it unfolds within a turn or a sequence of turns.

Returning to the factors which may impact upon the patient-provider relationship, structural factors such as appointments being time-bound, which I will expand on later in the chapter, and other institutional constraints may impact upon the quality of the communication between patients and health professionals. So far, it is becoming increasingly clear from the literature that patients and health professionals may hold dissimilar consultation expectations, which may be giving rise to some of the problems identified in these interactions. Indeed, the difference in patients' and health professionals' perceptions and understandings can be best captured in studies which have found that the two parties may even recall different accounts of the same consultation.

#### **2.11.4 Differing perceptions of the consultation**

Woodcock and Kinmonth (2001) found, in their interview study involving patients who had been newly diagnosed with T2DM, that there were notable discrepancies between nurses and patients' perception regarding the latter's concerns about their diabetes. The authors report that nurses identified patients' main concerns in only 20 percent of cases. Their study involved asking patients who had been newly diagnosed with T2DM what their main concerns were and these were frequently reported as being: 'fear of getting worse', 'difficulty in following dietary advice' and 'damage caused by diabetes'. Likewise, the 64 practice nurses with whom these patients consulted were asked to recall what their patients' main concerns were and they reported them as being: 'following dietary advice', 'illness or pain unrelated to diabetes' and 'issues to do with weight'. As the authors point out, these nurses underestimated the prevalence of patient concerns about 'damage caused by diabetes' and fear of getting worse and over-estimated concerns about non-diabetes matters. Their findings suggest that these discrepancies in the nurses' and patients' perceptions may arise because healthcare professionals are unaware of and fail to recognise patients' concerns. However, Woodcock and Kinmonth (2001) did not observe the actual consultations between pairs of nurses and patients so were unaware of what actually occurred in these consultations which gave rise to this mis-match between patients' and nurses' perspectives.

In another interview study by Parkin and Skinner (2003) they asked 141 consulting pairs, of patients and either a dietician or a nurse, to recall, on the same day that their consultations had taken place, the main issues that were discussed, and the key messages arising from their meeting. Alarming, they found that the two parties seemed to recall different consultations. Not only did patients report fewer topics being discussed, and fewer decisions being made about their treatment than their healthcare professionals, but they also reported many decisions and issues discussed that were not reported by their healthcare professional. One reason that Parkin and Skinner (2003) provide for this lack of agreement is related to professionals bringing their own agendas into the consultation which may explain the greater number of topics recalled by them as these were topics that they owned and wanted to discuss to complete their job. They explain that the patient may well be achieving a goal that they have set out to achieve but this may not resemble the healthcare professionals' aims. Adding to this, Ong et al.'s (1995) review of the consultation literature suggests that patients often do not recall or understand what the doctor has told them, and as the amount of information offered increases, the proportion recalled goes down (Roter and Hall, 1989). Given the findings from Parkin and Skinner's (2003) study, if health professionals and

patients cannot agree on or recall what is discussed between them then it is difficult to see how any decisions made about self-care and treatments are mutual or shared ones.

Although Parkin and Skinner's (2003) findings raise concern about the lack of concordance between patients' and health professionals' perceptions of their consultations, it is difficult to explore the reasons for why this is without looking at the actual consultation interactions. To this end, the studies discussed in this section have underscored the importance of observing consultations in order to better understand what processes and mechanisms are actually at play which may help to understand patients and providers discrepant views.

Another, but separate point to be made about the studies discussed is that Parkin and Skinner's (2003) and Woodcock and Kinmonth's (2001) studies involved nurses and dieticians who consulted with patients who had T2DM. Hampson et al. (1996) explain that often doctors feel under pressure and inadequately prepared to provide lifestyle counselling under considerable time pressures. To deal with this problem, other healthcare professionals, such as Diabetes Specialist Nurses (DSN) and dieticians who specialise in lifestyle issues provide this kind of support and expertise in addition to backing up the 'brief message' provided by doctors. It is concerning then that consultations involving healthcare professionals who can give more time and opportunity to patients to discuss concerns, work through barriers and agree on realistic barriers, may still have their own sets of problems.

Finally, the lack of time afforded to consultation has frequently been reported in the literature as a barrier to effective communication between patients and their providers. The availability of time to talk through the complexities and the implications of a chronic condition such as diabetes lies at the heart of both good patient care and patient empowerment (Pooley et al. 2001). The lack of sufficient time afforded in consultations has often been reported by providers and patients as being a barrier to mutual and frank communication. In Callaghan and William's (1994) study, for instance some patients reported feeling frustrated by the lack of time available to them to discuss worries and of being concerned about wasting the doctor's time. Consequently, they expressed a preference for nurses as they were not only seen as more accessible and approachable but as having more time for them, although, as described previously, these consultations may also be problematic.



In the final section of this chapter, I will briefly describe the patient-centred approach that has been recognised by healthcare researchers as a solution to some of the barriers to effective communication between health professionals and their patients.

## **2.12 Is a ‘patient- centred’ approach the answer?**

A patient-centred approach stresses the importance of understanding patients’ experiences of their illness and any relevant social and psychological factors (Stevenson et al. 2000). It involves providers employing active listening skills in order to encourage patients to express their agendas, help patients make informed decisions to achieve their goals, and overcome barriers through education, appropriate advice, and support, as well as working with patients to find common ground regarding management (Deber et al. 2007; Funnell and Anderson, 2004).

The consultation literature is dominated by studies which, broadly speaking, convey the message that the format of the consultations needs to move away from the traditional paternalistic approach to resemble a more collaborative one. Three main over-lapping reasons are behind this recommendation. Firstly, as described earlier, the traditional consultation structure was designed to deal with patients suffering from acute problems in which minimal patient participation was required, were often urgent, and the diseases that patients presented with were may have been reversible (acute) (Montori et al. 2006). As chronic illnesses became more prevalent, the same model was extended to these patients as well (Funnell, 2004). In recognition, that patients acquire a unique ‘expertise’ by living with and experiencing a chronic illness on a daily basis and that most of the choices and decisions about self-care occur in the patient’s ‘space’ (outside the consultations), researchers ask for patients to be made into equal partners (as both have knowledge which is relevant for the consultation) with their providers so that they can participate together in all phases of the consultation (Montori et al. 2006).

Secondly, the promotion of patients’ active involvement in the consultation involves granting them autonomy and ‘consumer rights’ (Ford et al. 2006; Edwards and Elwyn, 2006). This advocacy for patient-partnership in the consultation can be seen as a part of the wider political shift within the NHS in which patients are redefined as ‘consumers’ and the doctors as ‘service providers’ (Bissell et al. 2004).

Thirdly, there is (growing) evidence that shared-decision making approaches can achieve a range of health benefits (Edwards and Elwyn, 2006; Irwin and Richardson, 2006). In the context of patients with diabetes, there is evidence to suggest that interventions seeking to promote greater patient participation in decision making, such as patient coaching to empower the patient to ask questions and participate in decisions, has resulted in measurable improvements in quality of life and in physiological markers of the disease (Montori et al. 2006; Kaplan et al. 1989).

An assumption made by advocates of patient-centred care is that if patients are empowered to take responsibility for their disease and its management their adherence to treatments will improve (Montori et al. 2006; Edwards and Elwyn, 2006). In the context of diabetes, for patients to become empowered, they need knowledge and education about their disease and are taught problem-solving skills about their disease so that they can interact with their providers on an equal footing and apply their knowledge and understanding in dealing with their illness effectively (Funnell, 2004).

However, despite evidence demonstrating that a doctor-centred approach is not that effective with chronically ill patients and, a growing recognition that alternative methods are needed, there appears to be little evidence that the ‘shared-decision making’ approach has replaced the traditional dyadic relationship (Elwyn et al. 1999). As Edwards and Elwyn (2006) note, these models stem from theoretical frameworks and ethical considerations. They are widely advocated in policy terms but are not widely implemented in routine practice. Bauman et al. (2003) argues that the idea of patient-centred care may, in reality, be difficult to implement and pursue as it less clearly linked to immediate health gain especially in the case of diabetes. However, Montori et al. (2006) argue that it is the long-term process of establishing a partnership between patients and their providers that is crucial to foster the trust and mutual respect that will create an environment conducive to successful patient self-management. In any case, this ‘ideal-type’ scenario assumes healthcare professional continuity when, in reality, patients’ care, as described earlier, may be divided amongst different health professionals and, in some cases, between general practice and hospitals. Finally, Bissell et al. (2003) argue that patient centred care cannot ameliorate the material barriers (described earlier) to self-care regimen integration that are so often reported in studies researching patient perspectives and deflects attention from the material circumstances of patients’ lives, in the absence of a political commitment to address these concerns.

## 2.13 Summary

In this chapter, I began by describing how the traditional patient-provider relationship is governed by a set of rules, which as Parsons' described, was important to the functioning of society. In this relationship, the patient is the passive recipient of the providers 'superior' knowledge and technical expertise. I then discussed how changes in society, healthcare delivery and mortality and morbidity rates have raised questions about the paternalistic nature of the patient-provider interaction and how it may be considered problematic. Adding to this has been the growing concern about patients' difficulties in successfully self-managing their chronic illnesses. The form and content of the consultation has become the subject of growing interest because what occurs during it may be salient towards explaining why patients may have poor self-management. Indeed, it has been shown that patients may recall a different consultation to that recalled by their healthcare professionals. I have shown how the diabetes consultation, which is considered a cornerstone of good diabetes management, may not be giving rise to effective care. Many barriers to effective communication have been identified relating to patients' and healthcare professionals' consulting styles, patients' personal characteristics and structural/organisational constraints. To improve communication in consultations, researchers and policy makers have suggested that the patient-provider interaction needs to move away from the traditional, paternalistic style towards a more equal and patient-centred communication style. However, this shift is not widespread for various reasons described above.

Having highlighted some of the issues and concerns relating to consultations involving patients and providers who share the same first language and ethnicity, I will now turn my attention to the cross-cultural consultation. My study largely involved migrant Pakistani patients so it is crucial to determine what issues have so far been identified in consultations involving patients and providers who do not share the same first language and cultural backgrounds. In the following chapter, I will move onto describing some of these issues which will then be used to understand and explore some of the findings that arise out of this thesis. This chapter has raised several problems that have so far been identified in the patient-provider relationship and some of these will be further explored in the context of the cross-cultural consultation. These include knowledge levels in ethnic minority patients, South Asian perceptions of their consultation experience and the limited research which has looked at the interaction between ethnic minority patients and their health professionals. This literature will also be used to highlight how my study may contribute towards, and fits

within, this literature, and how the study's design may be a useful, innovative and, in-depth way of exploring some of the issues in the cross-cultural consultation.

## **CHAPTER THREE: CULTURE, LANGUAGE AND THE PATIENT-PROVIDER RELATIONSHIP**

### **3.1 Introduction**

In the previous chapter, I have shown how a multitude of ‘problems’ exist in consultations involving patients and providers who do speak the same first languages and share the same cultures. Now I will describe the challenges and issues arising in ‘cross-cultural’ consultations. For ease of reference, I will refer to consultations involving ethnic minority patients and their providers from non-minority ethnic backgrounds as ‘cross-cultural consultations’ as this is the term most frequently used in this literature. This term is used to encapsulate an array of differences between patients and providers such as language, ethnicity, and religious as well as cultural ones. By virtue of the UK being a diverse and multi-cultural society, patients and providers quite often do not speak the same language or share the same culture or ethnicity. However, few studies exist that have questioned and explored the quality of communication between ethnic minority patients and their healthcare professionals. In this chapter I will present an overview and appraisal of these studies which will also serve to provide justification for my research aims and the research design used in the current study.

In the first part of this chapter, I will describe some of the inequalities in health and healthcare which exist for ethnic minority patients. Seeking to understand why these inequalities exist, I will discuss how culture and cultural differences are thought to perpetuate poor service delivery to ethnic minority patients. Cultural differences are also drawn upon to partly explain the poor levels of diabetes knowledge reported amongst South Asian patients. I will describe how, despite the inequalities in health and healthcare experienced by South Asian patients, they generally report positive opinions about the health services received in the UK. Following on from this, I will argue that research into cross-cultural consultations has utilised limited methodologies and that simply relying on patients’ accounts to establish their ‘satisfaction’ with services is simply adequate. Then, I will describe how language is considered a major barrier in consultations and how it is commonly recommended that professional interpreters are a way of overcoming this barrier. Finally, I will describe some of the reported benefits and drawbacks of using professional and lay interpreters.

## 3.2 Disparities in health and healthcare

Significant inequalities exist in terms of people's risk of developing diabetes, their access to health services and the quality of those services, and in health outcomes (Department of Health, 2001). A number of studies have shown that most British ethnic minorities have higher rates of mortality and morbidity compared to the majority White population (Nazroo, 1998; Harding and Maxwell, 1997). The effect of migration itself may have a direct impact on health. Hull (1979) suggests that migration often leads to poorer health outcomes amongst migrants especially when the country they have migrated to is 'culturally dissimilar' from the home country and which may have a healthcare system with which they are unfamiliar. As mentioned earlier, not only is there a much higher incidence of T2DM amongst South Asians in Britain, they are also likely to develop the disease up to 10 years earlier than their White counterparts and, associated complications are encountered more commonly (Baradaran and Knill-Jones, 2004; Blakemore, 2000). Consequently, this condition and its complications account for a high proportion of avoidable morbidity and premature mortality in South Asians living in Britain (Swerdlow et al, 2004; Greenhalgh, 1997). The Scottish Diabetes framework action plan is specific in its aim to improve the quality of care and outcomes for all people with diabetes and to reduce inequalities. A crucial part of this is to ensure that the benefits are available to everyone which means proactively addressing inequalities. Tackling inequalities addresses the Race Relations Amendment Act (2000) which requires named public authorities, including the National Health Services, to remove discrimination and the possibility of discrimination and to actively promote 'race' equality.

Disparities in access to, and uptake of, healthcare services are quite often explained by the fact that people belonging to ethnic minority communities are quite often socially and economically disadvantaged. Most commentators agree that material factors have the largest role in explaining ethnic differences in health. Social disadvantage in terms of poverty, unemployment, poor housing and occupational differences are considered to have a negative effect on health (Rhodes and Nocon, 2003; Chandola, 2001; Blakemore, 2000; Greenhalgh, 1997).

Although the reasons for ethnic differences in the risk of T2DM and its complications are not entirely understood, a genetic susceptibility to the disease has also been used to account for its high prevalence amongst South Asians living in the UK. In particular South Asians have a genetic susceptibility to accumulate fat on the lower abdomen which is thought to be a risk

factor for diabetes (Greenhalgh, 1997). There is also some evidence for an insulin resistance syndrome among South Asian populations (Chandola, 2001).

### **3.3 Access to, and uptake of, health care services**

In order to understand why ethnic minority patients are faring so poorly in terms of their health, researchers have also paid considerable attention to the ways in which these patients utilise healthcare services compared with White patients. Ethnic-related differences in health service delivery and the uptake of services has been reported in several studies (Szczepura, 2005; David and Kendrick, 2004; Smaje and Grand, 1997). The general consensus is that equitable care is not easily accessible by, or being delivered to, ethnic minority patients which is contributing towards their poorer health and disease-management. Among other problems, racism and institutional discrimination can result in services which neglect the needs of ethnic minority patients (Schouten and Meeuwesen 2006; Blakemore, 2000). Also, reluctance to seek medical attention and lack of awareness of the availability of health care services may be contributing to the disparities in healthcare access (Shaukat et al, 1993) and the poor adherence seen in ethnic minority patients.

Although the evidence is sometimes incoherent and difficult to interpret (Goddard and Smith, 2001) some of the inequalities in healthcare include ethnic minority patients being less likely to be: (a) recommended for certain treatments than White patients (Schouten and Meeuwesen, 2006); (b) screened and included in health promotion activities (Swan, 1999); and, (c) provided with 'culturally competent' healthcare services (Goddard and Smith, 2001). In terms of access to diabetes care, David and Kendrick (2004) found in their audit study that compared with White patients and South Asians in Nottingham, UK that the latter were less likely to have their blood pressure or creatinine measured which are markers for detecting kidney failure. Also these patients were less likely to have an annual review appointment for their diabetes.

However, Fischbacher et al. (2009), who found contradictory evidence, carried out a database search which holds details of all patients known to have diabetes within the area served by NHS Tayside and extracted information about the number of South Asians recorded to have received diabetes care. They found that South Asians were more likely than non-South Asians to have had a structured review during the year under examination, and were just as likely as non-South Asians to have other measures carried out. However, despite this evidence that NHS Tayside are promoting equitable provision of care, the

outcome for diabetic control in South Asians is not as good as in the White population as was indicated in a London-based study by Chowdhury and Lasker (2002). Chowdhury and Lasker (2002) attempted to determine the prevalence of complications, and cardiovascular risk factors in early-onset type 2 diabetes and compared these results between White and South Asian patients. They found that South Asians had a higher prevalence of established macrovascular and microvascular complications compared to White patients. To understand why this may be, Rhodes and Nocon (2003) suggest that gaining access to services does not necessarily mean that patients' needs will be met appropriately. Szczepura (2005) also makes a valid point by suggesting that, even if certain groups use a service, they may still experience inferior quality of care, and therefore, poorer access. Thus definitions of 'access' that are limited to service uptake or 'receipt of care' are inadequate unless they consider the quality of care received by ethnic minority patients.

The planning and delivery of care services for ethnic minority patients has been called into question. Healthcare services are often criticised for not being 'culturally competent' by failing to take into account a person's language needs and cultural understandings. This may result in well-intentioned efforts backfiring which may result in negative health outcomes, in other words 'miscarried helping' (Wolpert and Anderson, 2001). The delivery of culturally insensitive services has often been implicated in the poor levels of health and illness (biomedical) knowledge observed in ethnic minority patients (Blakemore, 2000). In the following section, I will briefly describe the ways in which it is thought that culture and differences in cultural understandings can perpetuate poor service delivery to ethnic minority patients.

### **3.4 Culture and illness**

*'Culture is a social construct which is characterised by the behaviour and the attitudes of a social group. Determined by upbringing and choice, culture is constantly changing and is notoriously difficult to measure. Culture is usually defined by a set of norms, values and guidelines which individuals follow as members of a particular community. It tells them how to view the world, experience it emotionally and how to behave in relation others and other factors.'* (Naeem, 2003: p.114) .

Culture refers to integrated patterns of human behaviour that include the language, thoughts, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious or social groups (Anderson et al. 2003). Often language is included in the broad definition of culture. However, since language is particularly pertinent to the communication aspect of



the patient- provider relationship (and thus my research), I will discuss it in a separate section. Kleinman's (1983, 1988) seminal writings can be used to elaborate on Naeem's (2003) definition as he explains that illness is culturally shaped and the way we communicate about our health problems, the manner in which we present our symptoms, when and to whom we go for care and how we evaluate that care are all affected by cultural understandings and values (Kleinman et al, 1978).

To understand how cultural understandings may influence patient-provider communication, it is useful to draw upon Kleinman's (1983) concept of explanatory models which was described in the previous chapter. Not only are there discrepancies in patients' and providers' explanatory models due to the fundamental conflict between the medical model of disease and the patients' illness experience, these models may also be heavily influenced by cultural understandings and viewpoints. Culture impacts upon certain cognitive structures that mediate people's interpretation of physical and emotional states; for instance, the same symptoms may be seen to be indicative of different ailments depending on the cultural perspective in which they are considered. As highlighted in the previous chapter, the biomedical perspective which focuses on the physical dimension of disease is perceived to exclude the social and psychological dimensions of the illness experience. Helman (2000) argues that this perspective also excludes the cultural dimensions of ill-health which may heavily influence the meaning of the disease for individual patients.

This raises the question of how cultural differences and understandings are recognised in a healthcare context. Some studies which aim to explore 'cultural disparities' (e.g. Ferguson and Candib, 2002) by observing the patient-provider interaction often end up making recommendations on how the language barrier may be addressed instead. This is because there appears to be an overlap between language and cultural differences with the former considered as being part of a particular culture.

Other studies, notably by Greenhalgh et al. (1998) and more recently by, Lawton et al. (2006a & b) have explored how cultural understandings inform South Asians dietary practices and attitudes towards physical activity and, which may affect adherence to self-management strategies. It is reported that current diabetes services are operating within a typically Western cultural framework and, by not taking into account other cultural understandings, risk ostracising the needs of these patients. For instance Indian and Pakistani respondents in Lawton et al.'s (2006a) interview study described receiving

culturally insensitive dietary advice which did not tally with their cultural beliefs informing their lifestyles. In Thompson and Gifford's (2000) study involving Aborigines with type 2 diabetes, it was noted how diabetes care and advice was tailored to treat the individual in isolation of their family and community connections which could sometimes act to sever these important, identity-sustaining ties.

Most of these studies call for a change in the way services are delivered to ethnic minority groups but also recommend that patients need to be educated in an effective and culturally-sensitive way to enable them to change their (or adopt new) attitudes and, address some of the misconceptions they may have. For instance, Naeem (2003), in his Leeds-based survey study found that a large majority of Pakistani men with T2DM were failing to control and manage their condition, partly because of their fatalistic attitudes. For example, some respondents in his study believed that the fate and course of their illness was already pre-determined by god and nothing that they did could change that. Some also held the view that being overweight was a sign of health and affluence instead of a risk factor for diabetic complications. In light of his findings, Naeem (2003) recommended that there is a need to change Pakistani peoples' attitudes towards food and exercise and other diabetes-related risk factors by targeting men and women separately.

### **3.5 Knowledge of diabetes in ethnic minority patients**

As described in the previous chapter, knowledge alone is generally insufficient to enable patients to make lifestyle changes and effectively self-manage their condition (Knight et al. 2006). Patients need to be empowered and enabled to make the right choices, problem-solve and overcome barriers. Both health-related knowledge and empowerment are inter-related (Anderson et al. 1995). Patients need to have sufficient knowledge about their condition not only for self-management purposes but to be active participants in their consultations. Diabetes health knowledge includes knowing about: diabetic risk factors; the risk of long term complications; self-management techniques; how to solve problems; appropriate dietary plans; and, the importance of physical activity (Coates and Boore, 1996).

Hawthorne (1990) used questionnaire surveys to compare diabetes knowledge between South Asian and White patients with T2DM and found that, despite both groups receiving the same education, South Asians displayed a poorer understanding of their condition. Hawthorne (1990) accounted for this by explaining that the education delivered to Asian patients was often not relevant to their diets and customs. More recently, Lawton et al.

(2006a) in their patient interview study found that some patients perceived the treatment advice they were given by their health professionals as 'damaging' to their long-term health. In a separate interview study by Hawthorne and Tomlinson (1999) involving Pakistani patients with T2DM, they found that only a small proportion of their sample (15 per cent) said they attended their review appointments to learn about diabetes and how to control it themselves. Most attended to be told the results of their HbA1c and for reassurance. Around half of their sample was illiterate (especially women) and not only was knowledge about diabetic complications generally low but few women made the association between tight glycaemic control and the prevention of complications. Similar results were obtained from a survey study involving the Indian community in Coventry (UK) (Simmons et al. 1991). However, Baradaran and Knill-Jones (2004) found that South Asian patients who had had diabetes for a longer period were more knowledgeable about their disease. Similarly, Carrillo et al. (1999), in their discussion paper, argue that knowledge uptake may also be influenced by the levels of 'assimilation' or 'acculturation' by ethnic minority patients into their 'host' culture.

As previously discussed, poor levels of knowledge observed in South Asians is, in part, considered to be an artefact of the culturally insensitive healthcare services. However, Greenhalgh (1997) makes an important point by reminding us that many attitudes and behaviours in ethnic minority groups arise not because of strictly cultural or religious reasons but because these patients are poor, uneducated, unemployed, badly housed, or exposed to the fear of crime.

So far I have discussed how disparities in health and healthcare between ethnic minority and White patients have been attributed to several reasons including poor knowledge levels, lower socio-economic status and differences in health understandings and attitudes. I will now briefly draw attention to those few studies which have looked at South Asian patients' perceptions and experiences of diabetes health services. How patients perceive their health services, including the consultation, will set the context for my discussion given that literature about communication in the cross-cultural consultation is limited.

### **3.6 South Asian Patients' perceptions of UK health services**

It is generally reported in the literature that South Asian patients are satisfied with their healthcare services. In Lawton et al.'s (2006) interview study involving Indian and Pakistani patients, they claimed to be satisfied with the diabetes services they had received, partly

because they perceived them as better than those on the Indian subcontinent. Respondents in this study often commented that the healthcare services back in their homelands are expensive, technologically limited, and shaped by financial instead of humanitarian motives and not always accessible (Lawton et al, 2006; see also Hunte and Sultana, 1992). At this point it is briefly worth exploring the literature which describes how healthcare services are delivered to patients on the Indian sub-continent. Although this literature is patchy, it may provide some useful contextual information that might help explain some of the findings arising from this study.

Countries in South Asia are characterised by medical pluralism with biomedicine being the dominant form of healthcare which is often combined with traditional medical systems such as Ayurveda, a healthcare system based on ancient Indian beliefs to do with internal balance within the body (Hunte and Sultana, 1992; Datye et al. 2006). It is reported that privacy and confidentiality issues during the doctor-patient interaction are not considered as important as in Western societies and both the patient and the doctor expect the presence of family members who often negotiate and disclose information which they think is relevant to the consultation (Wilce, 1995). Doctors are reported to display a highly directive and paternalistic consulting style and, patients are deferent to their knowledge and expertise (Hunte and Sultana, 1992). However, Saradamma et al. (2000) report that, as healthcare provision is mainly encompassed within the (diverse and unregulated) private sector, which competes against popular traditional healers, patients can pick and choose who they consult with and may change doctors frequently, particularly if they perceive them to be providing ineffective medication. Effective medication are what patients on the Indian subcontinent are reported to strongly desire and perceive to be more important than the quality of the interaction with doctors (Hunte and Sultana, 1992). Thus, authoritarian approaches in the medical encounter and consumerist tendencies in choosing which physician to consult may co-exist. Healthcare has to be paid for on the Indian subcontinent so patients, particularly those who are poor, commonly self-medicate (Datye et al. 2006).

Returning to the argument that, generally speaking, South Asians claim to be satisfied with their healthcare services in the UK, Lawton et al. (2006a) explain that South Asians' may feel indebted towards the NHS because of their perceptions that healthcare in the UK is 'free' at the point of delivery and that healthcare professionals are not financially motivated during their consultations. Thus, they may feel they are not in a position to be critical. It could also be argued that their uncritical opinions reflect health services meeting their

perceived needs. However, as I described in the previous chapter, patients' expressed satisfaction with services, may be an artefact of how 'satisfaction' is measured or captured in survey or interview studies and it may not be such a useful way of exploring the quality of patients' interactions with their providers.

To summarise so far, South Asian patients' past experiences on the Indian sub-continent, their reported 'satisfaction' levels with UK health services, their poor diabetes knowledge and poor management of their condition, and, their cultural norms and ideas are all factors that have been identified as relevant to the interaction between these patients and diabetes services and the outcomes of these interactions. All these factors, although relevant, are 'external' to the patient- provider interaction and, in the following section, I will explore the few studies that have looked at how communication is enacted in the cross-cultural consultation. Before I look at these specific studies I will attempt to explain how the cross-cultural consultation may be influenced by the kinds of views that patients and providers bring to their interactions which are, in part, informed by the culture that they belong to. Conflicts between patients and providers may be explained using the 'individualistic'/'collectivist' dichotomy that has been recognised as a possible difference between cultures.

### **3.7 Individualism-collectivism construct**

One reason why the cross-cultural consultation is considered problematic is because Western medicine generally focuses on the individual patient, ignoring wider familial, social and economic issues which may also impact upon adherence. Schouten and Meeuwesen (2006) explain that communication can be difficult cross-culturally and, can be understood, in part, by an individualism-collectivism construct. According to such a construct people belonging to predominantly individualistic cultures see the self as an independent and autonomous entity, whereas in collectivist cultures the self is seen as part of the group. Personal goals are more important in individualistic cultures, while goals and norms of the group prevail in more collectivist-orientated societies.

Schouten and Meeuwesen (2006) suggest that South Asians who are collectively orientated are less assertive and less direct in their conversations than people belonging to Western cultures who are more individualistically orientated. Kim et al. (2001) explored the effects of patients' culture and cultural orientations on assertiveness and found that South Asians have fewer positive opinions about patient participation than Western participants and are less willing to be assertive. However, Schouten and Meeuwesen (2006) also note that the

individualism-collectivism construct, although useful in providing a framework for understanding some of the cultural differences in communication styles, does not take into consideration the heterogeneity in behaviour including the possible effects of migrating to and living within a predominantly individualistic culture and, of assimilation into this culture.

Furthermore, the ways in which ethnic minority patients communicate are not always thought to be due to cultural reasons. In the literature it is often unclear as to which communicative behaviours are due to cultural or language -related factors or are due to age, education and socio-economic status etc. For instance, Ferguson and Candib (2002) conducted a review to assess existing evidence for ethnic and racial disparities in the quality of the doctor-patient relationship. They concluded that patients who were not proficient in English were less likely to engender empathic responses from their healthcare professionals, establish rapport with doctors, receive sufficient information and be encouraged to participate in medical decision-making. Similarly, Perez-Stable et al. (1997) agree that factors which are associated with better health outcomes, such as effective information-gathering by patients and more affective exchange between patients and physicians, are largely dependent on language congruence. Unlike language-related difficulties, cultural discrepancies may be more difficult to identify as these differences are more subtle than language ones and problems in the patient-provider encounter may not be easily attributed to a consequence of an unshared culture.

Like the literature on consultations involving patients and healthcare professionals who share the same language and culture, the few studies which have examined cross-cultural consultations have also tended to focus on providers' communicative behaviours. For instance, Meeuwesen et al. (2006) conducted interviews with both indigenous Dutch and immigrant patients and observed their consultations with their Dutch GPs. They found that the consultations involving ethnic minority patients were shorter than with other groups and also that the doctors were more verbally dominant. They also found that healthcare providers expressed less affective behaviour towards ethnic minority patients. The authors speculate that, due to unshared language, GPs invested relatively more time trying to understand what these patients were saying through paraphrasing and asking for clarification, which left less time for them to be 'affective' towards their patients.

This finding is echoed in a similar study conducted by Neal et al. (2006) in the UK who observed consultations and compared the ways in which White and South Asian patients communicate with White GPs. Although they found that South Asian patients who were not fluent in English had longer consultations than White patients they also found that White patients had longer consultations than South Asian patients who were fluent in English. Similar to Meeuwesen et al. (2006) the authors of this study observed how doctors spent more time asking questions and less time giving information to South Asian patients. Neal et al (2006), in their work on consultations, assert then, on the whole, even when South Asian patients were fluent in English their consultation time was shorter than with White patients and less appeared to happen within the consultation. This study also confirmed Meeuwesen et al's (2006) finding that most of the content in the consultations involving ethnic minority patients was instrumental and not affective. However, the authors of these studies do not present a reason for why this may be and suggest that further research needs to be undertaken to understand why.

Rosenberg et al. (2007a) interviewed 25 GPs (in Canada) to understand the strategies that they used when consulting with patients from cultures other than their own and identified two approaches that GPs used. They termed these strategies as 'patient adaptation' and 'physician adaptation'. The former refers to when physicians insist on giving patients choices even if patients, back in their original homelands, had been used to physicians who were highly directive /authoritarian and thus they were not used to having choices. The latter term was used to encapsulate providers who recognised their own biases and worked to adapt and overcome them and recognise/ treat patients who may have different understandings to themselves. Whatever strategy was adopted, the doctors in this study reported feeling uncomfortable because they felt they had little knowledge about patients' cultures or even a framework to elicit information about their culture. Their choice of strategy depended on the topic discussed; for instance, they claimed to adopt a patient adaptation strategy when dealing with issues they felt deeply about such as the autonomy of women. Some doctors also described how a patient's appearance influenced their thinking. As one doctor commented: '*When I see a veiled woman I see the veil first*' [Rosenberg et al. 2007: p.148].

Sometimes GPs actively avoid drawing attention to cultural differences. Wachtler et al. (2006) elicited Swedish GP's perspectives on their experiences of consulting with ethnic minority patients using semi-structured interviews and found that cultural difference did not

feature strongly in their minds when treating patients. In fact GP's were reported to have avoided addressing pronounced cultural differences in their efforts to treat all patients equally. Wachtler et al. (2006) comment that this may be a problem because, when mutual understanding is poor and the consultation not 'successful', cultural differences are central. The difference in the findings from this study and the one by Rosenberg et al. (2007a) is difficult to explain because both studies used the same methods i.e. interviews with GPs. However, these contradictory findings highlight the importance of observing consultations in order to see how GPs (and other health professionals) interact with their patients in practice instead of simply relying on their accounts. Indeed before looking further at barriers in cross-cultural consultation, it is worth reflecting on some of the limitations of the study designs used in the research summarised thus far.

As mentioned earlier, there have been very few studies that have directly observed consultations and the limited number of observational studies that have been conducted in the UK and other European countries, as well as the US, have predominantly been quantitative. Many of these studies (e.g. Ford et al. 2006 and Bensing et al. 2006) have made use of frequency systems (such as the Roter interactional system and Bales) that focus on the relational aspects of communication such as instrumental versus affective dimensions of communicative behaviour, thereby neglecting other, more context-related aspects of communication. Indeed, frequency counting of behaviour does not shed light on the dynamics of the communication process, thereby running the risk of leaving essential difficulties in cross-cultural communication undetected and unexplained. Schouten and Meeuwesen (2006) comment, in their review of observational studies on cross-cultural consultations, that few explanations are provided which help to make sense of why patients and healthcare professionals display certain "communicative behaviours".

### **3.8 A Language barrier and interpreters as "solutions"**

While cultural barriers are sometimes difficult to ascertain and there appears to be few suggestions to overcome these beyond making services culturally sensitive/competent, a language barrier on other hand is easier to recognise and indeed has received the greatest attention for the reasons alluded to earlier in the chapter. In Europe and the US it is quite common for consultations to take place between providers and patients who have limited English, without the aid of a professional interpreter (MacFarlane et al. 2009; Bischoff et al. 2003). There is a general consensus amongst researchers interested in cross-cultural communication that the lack of a common language between the health professional and



patient is an obstacle to adequate healthcare delivery. Studies which have compared language concordant consultations with language discordant consultations have shown that language concordance tends to be associated with better adherence to self-management strategies (Carter-Pokras et al. 2004), improved appointment keeping and fewer emergency visits (Manson, 1988), improved health outcomes (Perez-Stable et al. 1997) and higher patient 'satisfaction' (Morales et al. 1999). However, what is unclear in this literature is in what ways language discordance affects the quality of communication in these consultations (Schouten and Meeuwesen, 2006). Quite often language barriers are considered together with cultural ones making it difficult to disentangle what communicative issues arise from which aspects of the cross-cultural interaction.

Unlike cultural barriers, it seems language barriers are considered to have a more definitive solution. Using professional interpreters, who are formally trained to interpret for clients and professionals, are widely considered to be an appropriate way of overcoming the language barrier in cross-cultural consultations (MacFarlane et al, 2009; Bischoff et al, 2003; Hornberger et al, 1996). A recent report published by NHS Health Scotland (2009) sets out interpreting guidelines for NHS staff in Scotland and stipulates that healthcare staff should use interpreters to enable them to provide high quality care and services through effective communication. Several studies report benefits of using interpreters upon patient-provider communication, service uptake, clinical outcomes and patient 'satisfaction' with care (Karliner et al., 2007; Meeuwesen et al. 2006; Bischoff et al. 2003). Interpreters allegedly reduce the scope for wrong diagnosis and treatment, enable patients to make choices and understand their treatments, and reduce repeat visits (Health Scotland, 2009). Despite these claims, little research has systematically explored cross-cultural consultations involving interpreters to understand the reasons why communication is supposedly better.

Interpreters are supposedly fluent in the language of the provider and the patient and facilitate communication by conveying information between the two parties. As well as professional interpreters, many patients choose to be accompanied by family or friends who can interpret for them (Rhodes and Nocon, 2003). Family or friends acting as interpreters are usually referred to in the literature as 'informal', 'ad-hoc' or 'lay' interpreters (Rosenberg et al. 2007; Jentsch, 1998). Whilst UK policy guidelines discourage the use of informal interpreters (especially children), concern has been expressed about a lack of adequate professional interpretation services (McPake et al. 2002). According to the McPake et al. (2002) a core element of developing culturally sensitive services is the

provision of more interpreters who are easily accessible to both patients and their healthcare providers. Greenhalgh et al. (2007) suggests that the development of strong and efficient procedures for providing an effective interpreting service to patients will address some of the challenges posed by a diverse multi-lingual society.

Although more research is needed to shed light upon how the triadic consultation is enacted there has been growing interest in understanding the various roles that professional interpreters adopt in cross-cultural consultations. According to a report by NHS Health Scotland (2009), professionally trained interpreters are neutral, independent, and responsible for keeping all information confidential. They should only interpret what is said and only intervene for clarification or repetition and should not take sides. However, Hsieh (2006; 2007), who conducted an observational and interview study involving professional interpreters, general practice patients and healthcare providers, argues that this type of image reflects an interpreter as a 'conduit' simply transmitting messages in a 'machine-like manner' between parties reliably and without distortion. Based on her findings, Hsieh (2006) argues that this may be an over-simplification of the interpreter's role. Hsieh (2006) argues that, in reality, the interpreter's role is ambiguous and they do more than merely switch words from one language into another in an impartial manner.

The use of interpreters transforms the medical dialogue into a three way interaction (Rosenberg et al, 2007) and interpreters' actions can have a profound influence on the messages conveyed in these consultations. Interpreters' roles and actions may be influenced and shaped by a number of complex factors including patients' and providers' expectations, institutional arrangements and their own perceptions about their roles (Hsieh, 2006).

Hsieh's (2007) research on interpreters' roles has been insightful and has begun to address the gaps in the current literature on communication using interpreters in medical consultations. She found that interpreters often acted as 'co-diagnosticians' in which their roles appeared to over-lap with the provider's role. Five interpreter strategies were identified as co-diagnostician behaviours: (a) assuming the provider's communicative goals (evaluating whether these goals have been met and deciding to independently pursue the provider's goals by, for instance, initiating information re-seeking on behalf of the provider); (b) editing patient information after assessing whether it has medical value or not; (c) initiating information seeking about illness-related information when the providers are present; (d) participating in diagnostic tasks by collaborating with providers to investigate information,

examine physical symptoms and so on; and, (e) independently volunteering medically related information to patients. The overall effect of these strategies was that the interpreters in Hsieh's study tended to emphasise the providers' role and medical information and reinforced the hierarchy in healthcare settings. Interpreters in this study saw these behaviours as complementary, rather than detrimental to, the communication process and argued that their experience and cultural background allowed them to provide services (or mend the problems created by culturally inappropriate services) which health professionals were unable to offer. She also found that interpreters justified their co-diagnostician role by stating that they saw themselves as part of the healthcare team and thus were providing services as part of this team. Some of these findings are enhanced by Davidson's (2001) observational study of hospital based interpreters, who found that professional interpreters often colluded with healthcare professionals and sometimes prevented patients' questions from reaching the healthcare professional. Although considered as an undesirable option these interpreters claimed to side with the healthcare professionals in order to preserve their limited time. However, Hsieh (2006; 2007) points out that this type of interpreter role can also be seen as problematic, undermining the patient-professional relationship and the providers 'symbolic power' by the interpreter taking on some of the provider's role as healer.

It has also been reported that the institutional culture, including hierarchical positions, policies and regulations necessitate interpreters to do more than simply interpret. As already mentioned, time is a major constraint in a triadic consultation and Greenhalgh et al. (2006) recommend that 'double appointments' should be booked to accommodate this complex three-way interaction. Also, because of the way clinics are organised, interpreters can spend a significant amount of time with patients alone outside the consultation (for example in the waiting room) which, Hsieh (2007) speculates, may influence the consultation interaction as patients and their interpreter may get an opportunity to discuss information related to the consultation prior to the consultation. Hence Hsieh (2007) calls for research examining interpreters' roles and functions outside as well as inside the consultation.

Furthermore, differences in social class, education and personal beliefs between patients and interpreters may have a bearing upon the triadic consultation interaction (Davidson, 2001). For instance patients' fatalistic attitudes regarding their illness may clash with the thoughts and beliefs of an interpreter who (perhaps through their experiences or education) may view things differently. These differences may discourage interpreters from conveying

information from the patient to the provider which they deem to be traditional, 'folk' or 'non-medical' (Davidson, 2001).

However, contradictory evidence exists regarding the roles of professional interpreters, for instance, Rosenberg et al. (2007) encourage the use of professional interpreters based on their findings that they act mainly to ensure information transfer in comparison to lay interpreters who act mainly as a third participant often speaking as themselves rather than rendering the words of the doctor and patient into the other's language. On the basis of their findings, Rosenberg et al. (2007) urge health professionals not to use lay interpreters as they are less likely to accurately transfer information compared with professional interpreters. Echoing Rosenberg et al.'s (2007) recommendation Health Scotland's (2009) report and other contemporary health policies also discourage using family or friends as interpreters. Some of the reasons provided for this include: the loss of confidentiality; non-guarantee of accurate interpretation; patients may not wish to discuss personal/sensitive issues in the presence of family/friends; a potential for a conflict of interest between patient and family/friend: and, it may compromise patient safety and rights. The report further states that, attempting to 'muddle through' with a patient's family or friend is simply not good practice. Despite the various concerns articulated, and the extensive use of family and friends (NHS Health Scotland, 2009; Davidson, 2001) consultations involving lay interpreters are an even more under-researched than those involving professionals (Greenhalgh et al. 2006).

Within the South Asian community lay interpreters commonly accompany patients to their consultations to help overcome the language barrier (Rhodes and Nocon, 2003). As described earlier this may be partly because on the Indian sub-continent it is common etiquette for relatives to come along to consultations. Family interpreters may be daughters, sons, wives and husbands and sometimes (particularly in the Bangladeshi community) young children (MacFarlane et al. 2009; Rhodes and Nocon, 2003). From the perspectives of patients and researchers, several reasons have been given for the use of lay interpreters. Davidson et al. (2001) suggest that lay interpreters are used when there is a lack of availability of professional interpreters. However, other researchers argue that lay interpreters may be preferred by patients because of issues to do with confidentiality and trust. South Asian patients in the UK may be hesitant to use professional interpreters who are also part of their community due to concerns that confidential issues related to their health might be disclosed to other members of their community (Greenhalgh et al. 2006). Also, lay interpreters may provide personal support and share an understanding with the patient that

extends beyond the clinical setting (Rhodes and Nocon, 2003). By virtue of living with the patient and mediating their medical consultations, lay interpreters may acquire more knowledge about the patient's condition than the patient themselves and, therefore be in a position to advise and guide the patient (Alexander et al. 2004). Lay interpreters are also more likely to side with patients during consultations, not only because they have a vested interest in the patient's health but also because they have a deeper understanding of, and sympathy for, the patient's life-world (Alexander et al, 2004).

However drawbacks to using lay interpreters have also been highlighted. Rhodes and Nocon (2003) suggest that patients and lay interpreters may experience embarrassment when a sensitive topic is discussed, such as the use of contraception. Lay interpreters may lack knowledge of service procedures and specialist terms and may not have the skills needed to interpret accurately, potentially hindering effective communication in the consultation (Rosenberg et al, 2007). For instance, in Rosenberg et al.'s (2007) study which explored healthcare professionals' perspectives and experiences of dealing with lay and professional interpreters, some providers felt that family members did not always translate the treatment plan to the patient.

Rosenberg et al. (2007) also found that health professionals worked differently with lay and professional interpreters. For example, health professionals trained to use interpreters would follow the communication rules (setting agendas and time management) that they were taught as part of their training when dealing with professional interpreters. However the same health professionals said that they acted as though these rules did not apply when it came to lay interpreters as they also perceived them to play the role of care-givers and, did not expect that they would translate in the same way as professional interpreters would. Nevertheless, how interpreters (whether lay or professional) influence and affect the communication process in the triadic cross-cultural consultation needs to be better understood. It is now established that interpreters' roles are far more complex than the 'conduit' role still advocated in policy and practice. Further research needs to be undertaken to understand the implications of this for the patient-provider interaction through observational studies.

### **3.9 Summary**

In this chapter, I have described some of the limited research that has been undertaken to explore the patient-provider interaction in the cross-cultural consultation. Given the major

inequalities that exist between UK South Asians and White patients with diabetes, in terms of their health and healthcare delivery, it is concerning that only a few studies have attempted to look at how providers are communicating with these patients. Nevertheless, what this chapter has highlighted is that there may be a number of barriers to South Asian patients' access to, and uptake of, healthcare services as well as their engagement with their providers. These barriers may relate to cultural and language differences but also to material and socio-economic differences experienced by ethnic minority patients. The use of professional interpreters is a common recommendation proposed as a solution to address the language barrier and improve the quality of the patient-provider interaction. It is recognised that lay interpreters are still widely used however the message appears to be that where possible professional interpreters should be used as they are considered to provide accurate translations and are not perceived by health professionals as care-givers.

Finally, what this chapter underscores is a need for more exploratory research into the cross-cultural consultation. Very few studies have observed this kind of consultation, and those that have, have not complemented their observations with patients' and providers' accounts of their experiences of the consultation interaction. The results of patient 'satisfaction' surveys does not help us to ascertain what takes place in these consultations and similarly research limited to patient interviews provides a narrow and subjective view of the consultation interaction. Similarly, the triadic consultation is relatively under-explored and researchers have mainly relied on interpreters/providers and/or patients' views and perceptions of using interpreters during their consultations. Without observing the patient-interpreter-provider interaction, these accounts are conjecture because they cannot be compared and contrasted to the actual interaction. Unless, the triadic consultation is directly observed it is difficult to understand and explore the processes of communication that take place between the three parties and how information is exchanged through an interpreter.

To this end, in my study I propose a research design which will address the following study aims:

- To explore the perceptions and experiences of diabetes consultations from the perspectives of Pakistani patients, their healthcare professionals and interpreters (when one is involved).
- Identify some of the 'barriers' and 'facilitators' to effective communication between healthcare professionals and Pakistani patients.

In the following chapter I will describe the methods I used to achieve these aims.

## **CHAPTER FOUR: STUDY DESIGN**

### **4.1 Introduction**

In this chapter, I provide a detailed description of the research design, the reasons behind my choice of methodology, and how this design addresses the aims of this study. The data for this study were compiled in the form of case studies and, the individual methods used to achieve these will be described as well as the strengths and limitations of this methodological approach. The processes deployed to recruit different types of participants (i.e. health professionals, Pakistani patients and interpreters) will also be explained and details about the sample provided.

### **4.2 Theoretical stance**

Before the methods used in this study are described, the epistemological position that informs both the nature of this study and ultimately the ‘knowledge’ that is produced from it, needs to be made clear. The theoretical view point that I have chosen to inform this study is ‘Social constructionism’. Social constructionism is an epistemological stance which rejects the objectivist view that reality exists outside consciousness (Crotty, 1998). Social constructionism claims that truth or meaning comes into existence through human engagement; in other words, meaning is not discovered but constructed. The nature of this research study, which is concerned with how, and in what ways, people communicate with each other, and how they create meaning during social interaction, lends itself to a symbolic interactionist viewpoint which is a theoretical strand of social constructionism. A basic tenet of symbolic interactionism is that society is studied from the individuals’ own concrete perspectives, with a focus on people’s meanings of events, and how they present and construct the ‘self’ (identity) (Goffman, 1959). Its concern with micro-level interactions allows for an exploration of the practical and social elements of the patient-provider relationship. Furthermore, within this perspective the position of all parties is given equal importance; in other words, the patients’ illness experience is equally important and as credible as the provider’s ‘expertise’. At the heart of this perspective, is being able to put ourselves in the place of others and to recognise that different people may construct meanings about the same phenomena in different ways. Therefore, the methodological design for this study is underpinned by a theoretical perspective, which seeks to understand

and explore how meaning is created, in terms of communication, in the patient-provider interaction, and from the standpoint and perspectives of all parties concerned.

I will now describe the methods I used in my thesis and explain and justify why I chose them. This study employed a prospective design which combined in-depth interviews with observations of consultations. I begin by justifying why I used two rather than one method to gather the data for this study.

### **4.3 Observing the consultation**

The idea of observing consultations first arose from an interview study, involving Indian and Pakistani patients with T2DM, which was conducted shortly before the start of this doctoral research (see Lawton et al. 2006 a&b). Although the interviews conducted as part of this study provided some invaluable insight into patients' care experience, it was also found that during their interviews, patients would often allude to issues that occurred during their consultations. It became apparent that interviews alone could not tease out these issues, as these reflected what patients chose to share in their accounts. What was needed was some form of first-hand insight into the actual consultations.

Observational research is commonly conducted in a variety of different settings, including, in the patient-provider consultation (Radley et al, 2008; Somerville et al, 2008; Stevenson et al, 2000). It is the preferred method because it enables the researcher to get 'up close' to the encounter (Denzin and Lincoln, 1998). Observational techniques are used to investigate social practices rather than perceptions (Silverman, 1993). From an interpretative perspective, observational approaches situate the 'object of inquiry' within its 'natural' setting, and the context is very much part of the phenomena to be studied.

Erving Goffman (1959), through his seminal observational studies, is considered a pioneer in introducing a different perspective to what seemed 'unremarkable' face-to-face encounters. Goffman (1959) was concerned with how subjective meaning and identity is situated and created from within the social context in which interactions occur. He was particularly interested in the way people shared 'symbols', (for instance language, gestures and actions) which provide the interpretations through which they construct their behaviour, relationships and institutions. In 'The Presentation of Self in Everyday Life' (1959), he describes the 'self' as a product of the encounters created out of impressions from other 'actors' in the social situation. People choose ways to present themselves, based on their calculations,



assessments, and judgements of the social setting, and those with whom they are interacting. Goffman (1959), in his observations of the medical encounter, describes how both the provider and patient dictate and shape the format and nature of the consultation by 'performing roles' that are expected of them. The provider will be the authoritarian 'expert', and the patient will play a passive role, this arrangement being commonly referred to as a paternalistic consulting style. By fulfilling their roles, the 'ceremonial order' of the consultation is preserved, which is essentially a series of negotiations that assist in maintaining the assumed 'order' of the consultation. Based on reading Goffman's work the idea of directly observing consultations further appealed to me as I became interested in exploring how this ritualistic, 'ceremonial' format of the patient-provider may be played out in cross-cultural interactions. Patients may experience different 'rituals' in their UK consultations than compared with their experience of consultations in their original homelands.

Having decided to undertake observational work, I also had to decide what kind of an observer I would be during these consultation interactions. Part of this decision was informed by commonsense, in that I wanted to observe in a way that had minimal impact on the patient-provider interaction. My decision was also informed by the methodological literature which has shown that observation can be participatory or non-participatory, and covert or overt. In the following section I will discuss some theoretical ideas behind each of these methods of observation, and justify why I decided that non-participant observation was the approach best suited to this study.

#### **4.3.1 Participant observation**

Participant observation, a term synonymous with ethnography and ethnomethodology, is a qualitative method which involves the observer participating in the activities of the group being observed (Jorgensen, 1989). Participant observation can be covert, whereby the investigation is concealed, and the researcher pretends to be a 'normal' member of the group (Gilgun et al., 1992). However this may raise serious ethical issues as participants would be denied the opportunity to give their informed consent. Overt observational studies, on the other hand, require researchers to be honest about their role in the group (Jorgensen, 1989). Gaining access overtly to the desired setting can be difficult, as participants may be suspicious of the researcher's motive, particularly people belonging to small local communities (Bowling, 1997). It is likely that this type of observation will have an effect upon participants' behaviours and their actions, as they may feel 'watched', particularly

when the researcher initially attempts to forge relationships with the participants under observation (Jorgensen, 1989). For the purposes of my study, participant observation was not an option as I intended on observing, and not participating in, the patient-provider interaction.

#### **4.3.2 Non-participation observation**

Non-participation observation differs from the participatory style in that the researcher is not part of the setting he or she is attempting to investigate (Bowling, 1997). This type of observation can also be either overt or covert. This method enables the researcher to observe a situation from a detached and discreet position, while avoiding any involvement in the observed interaction(s). In these circumstances, the researcher is metaphorically likened to a 'fly on the wall' (Robson, 1993), although this is not entirely the case as the researcher's presence will influence the interaction to some degree. One commonly cited example illustrating the observer's influence is the 'Hawthorne effect' (Robson, 1993), a term coined during a research project, (1927 - 1932) involving the Hawthorne Plant of the Western Electric Company in Cicero, Illinois. The study found that the production of the workers improved, regardless of the experimental manipulation employed (e.g. brightness of lights, humidity). It was concluded that the workers were 'positively' affected by the presence of the researchers, thereby working harder under their watchful gaze.

Despite the reactivity that may be caused by researchers who choose to observe, direct observation offers an invaluable opportunity to understand a phenomena in a real-life setting, in real-time and in its 'natural' context (Robson, 1993). Given that I wanted to understand the consultation experience from the 'insider's' perspective within its real setting, by being there and watching the encounter, I decided that non-participant observation afforded me the best means to do so. In this way, I did not have to rely on peoples' accounts to gather data, instead I could watch what they did and listen to what they said (Robson, 1993). Non-participant observation also offered me a way to identify social processes and explore what goes on in a diabetes consultation without interrupting the 'natural' flow of events. Although this did not prove to be entirely possible, in practice as will become evident when I describe my findings, the objective of using this method is to enable the observed interaction to progress in the same way it would have had I not been there.

In the following section, I explain how my plans for interviewing the study respondents would serve to complement, and add more insight to the observational component of this study.

#### **4.4 Qualitative Interviewing**

Research methods utilising survey or questionnaire designs risk losing valuable information with their use of standard, pre-coded questions. Qualitative interviewing, by contrast, appeared the most appropriate and effective choice available, because it is a much less structured approach and the interviewer can respond to the direction in which interviewees take the interview. Qualitative interviewing is, in essence, ‘a conversation with a purpose’ in which the researcher can achieve rich and detailed answers from the interviewee (Robson, 1993). It is a situation where one person talks and another listens for the purposes of obtaining research-relevant information (Silverman, 1993). The primary issue is to generate data, which give an authentic insight into people’s experiences (Robson, 1993). In-depth interviewing, as a method, draws upon interpretivist epistemological and ontological positions similar to those underpinning observational methods. Qualitative interviewing places a clear emphasis on the perspectives and accounts of those being interviewed, and adds depth to the research (Robson, 1993). This method allows respondents to tell their own stories in their own words during a focussed interaction. The interactive element means that the interviewer has the privilege of exploring how respondents articulate their accounts and the meanings that may lie beyond what they initially say. The social context of the interview is intrinsic to understanding how narratives are constructed. In-depth interviewing is a flexible and sensitive approach, which enables researchers to obtain a solid understanding of what they want to know, and much more (Denzin and Lincoln, 1998).

In theory then, interviews appeared to be a suitable method to achieve some of the study’s aims as they provide an effective means of gaining a narrative which was embedded in the interviewees’ social, cultural, and religious contexts. My next decision was how and when I would do the interviews with patients to tie in and enhance the data and insights generated through consultation observations.

It made sense to either interview patients before or after their consultation, since the questions would be based around their views and experiences of the consultation that I would be observing. However, since the consultation would be the focal point of these interviews, I recognised that the questions I would need to ask patients before a consultation

would differ markedly from those asked after the consultation. For instance, in pre-consultation interviews, I would be asking patients to look ahead to their consultations and describe what they expected from it. Also, these interviews would be a useful opportunity to ask patients about their past experiences of healthcare, and obtain some insight into their life circumstances. On the other hand, I envisaged that the post-consultation interviews with patients would be fairly focussed upon the consultation interaction that I would have observed, and what had occurred during it instead of, for instance, their pre-consultation expectations. Hence I realised that choosing to do only one interview with each patient would risk missing important information. Therefore, since both interviews served different purposes and, could potentially provide different insights, I decided to do pre-and post-consultation interviews with each patient who took part in the study. My decision was further reinforced by a study carried out by Barry et al. (2000; 2001), who conducted pre-consultation interviews with patients in order establish what agendas they proposed to raise in their GP consultation and, after observing their consultations, used their post-consultation interviews with these patients to explore and understand why they did not voice all their agendas with their GPs that they had intended on raising before their consultations. This study underscored the importance of combining pre- and post-consultation interviews as the authors of the study may have missed the agendas that patients did not raise during their consultation, had they only interviewed them after their consultation. Likewise, had the authors chosen to conduct only pre-consultation interviews, then they would have missed the opportunity to explore why patients did not raise issues that they said they would in their consultations. In the following section, I will discuss how I decided on the kinds of questions to be included in the topic guides for these interviews.

#### **4.4.1 Pre-consultation interviews with patients**

I decided to conduct the initial interviews with patients a few days before their scheduled diabetes consultations, as I envisaged it would be easier to reflect upon an appointment that was only a few days away, rather than in several weeks time. I saw these interviews not only as presenting an opportunity to help me establish a rapport with these patients but also to learn about how diabetes affected them on a day-to-day basis, as well as their expectations and understandings of their scheduled consultation. Specifically, I used these interviews to explore:

- Their understandings of why they thought they were attending the consultation.
- How significant they felt these consultations were for their diabetes management.

- What kinds of issues or information patients perceived as relevant to raise and discuss in their consultations and why they might choose to talk about some issues and not others.
- What patients hoped to gain from their consultations.
- How patients communicated with their health professionals (i.e. through an interpreter).
- Patients' perceptions of their quality of interaction with health professionals.
- Patients' perceptions of their previous healthcare experiences.
- Patients' past experiences of their consultations including in their original homelands.
- How patients managed their diabetes in the context of their life circumstances and whether their self-care was influenced by any cultural/religious factors.
- Patients' broader life circumstances and whether these had any impact on how they perceived their consultations.
- Other matters that arose in the context of the interview.

These interviews could then be compared to what was actually discussed in the consultation and also my post-consultation interviews with the patients. The interview schedule for patients' pre-consultation interview is attached in appendix 1a.

#### **4.4.2 Post-consultation interview with patients**

I decided to conduct these interviews soon after the consultation, whilst the consultation experience was still fresh in patients' minds. In these interviews, I discussed with the patient what had happened in the consultation first observed, and encourage him/her to reflect upon the experience. Questions in these interviews were based on the consultation interaction, and also on some of the issues that patients had raised in their pre-consultation interviews which might be relevant to reflect upon in light of the consultation observed. In asking patients to look back on their consultations, some of questions in these interviews included:

- How successful (or not) patients had perceived the consultation to have been.
- Whether and why it met with their expectations.
- What patients thought the main messages arising from their consultation were.
- In light of my observations, why some patients may not raise issues or concerns that they said they would during their pre-consultation interviews.

- How important patients perceived the advice and recommendations provided by their health professionals to be.
- Whether patients perceived any difficulty when communicating with their health professionals.
- Whether patients would make any changes to their diabetes management in light of recent advice.

Interview schedules thus had to be tailored to take into account the observed consultation and what happened during it. If an interpreter was involved in the consultation then some of the questions also had to be around this aspect of the consultation. An example of a tailored post-consultation interview schedule is in appendix 1b. In these topic guides, examples of what happened in the consultation were recounted to the patient so that they could offer their reflections on what happened.

#### **4.4.3 Interviews with health professionals**

As part of this study, I also chose to interview those healthcare professionals involved in the consultations I observed, in order to understand their experiences, and what they perceived to be the main barriers/facilitators to effective communication. Key areas explored in the health professional interviews included:

- Health professionals' perceptions of how successful the consultation had been and why.
- The main messages that they had intended to deliver to the patient, and their perceived success in delivering them.
- Whether health professionals perceived there to be any difficulties in communicating with patients during the consultation, and why.
- Whether health professionals felt that language difference was an issue in their consultation.
- Whether health professionals thought that the patient had voiced all their concerns and issues they had intended on raising.
- Previous experiences of consulting with Pakistani patients and of using interpreters.

If there were incidents during the consultation in which an error in communication occurred, or messages were not conveyed between the patient and the health professional, then the

reasons for these were explored in the interviews through focussing upon how health professionals' 'saw' the consultation, and whether they were aware of any such incidents. If an interpreter was present during the consultation then questions were structured to elicit health professionals' experiences and views of interpreters' roles and actions in these consultations. Like the patients' post-consultation interviews, these interview schedules were tailored to the individual patient-provider interaction that I had observed. An example topic guide of an interview with a health professional is attached in appendix 1c.

I decided that a pre-consultation interview with health professionals (or interpreters) was an impractical option. Health professionals, particularly those consulting with several patients on a daily basis, would understandably have difficulty recalling who individual patients were, let alone what was going to be discussed during these consultations. Asking health professionals to retrieve and read patient's medical notes prior to a potential interview would also be an unreasonable request given that health professionals' have a heavy work load and I was already requesting time out of their busy schedules to take part in a post-consultation interview. It is difficult to know how much valuable insight I might have gained, had I interviewed providers before their consultations. However, I assumed that they would provide more generic information and responses than those offered by patients. I decided to elicit this type of information, including what providers expected from their consultations with patients, during their post-consultation interviews.

Although there are no exact figures on how many Pakistani patients attend with interpreters in Edinburgh, patients are commonly accompanied by interpreters. Thus, to gain another layer of insight, and an alternative perspective on the consultation interaction, I considered it important to engage with the interpreters who I would be observing as part of this study.

#### **4.4.4 Interviews with interpreters**

Like with the health professionals, I decided to conduct interviews with the interpreters that were involved in this study, after the observed consultation, having established that undertaking interviews prior to the consultation would not be feasible. I spoke to the 'Interpreter and Translating' agency who offer professional interpreter services to hospitals in Edinburgh, and I established that interpreter requests are usually dealt with close to the time of the appointment, and are dependent on who is available on the day. In these interviews, I decided to ask about their general experiences of interpreting, as well as specific questions about the consultation that I observed. Key areas explored included:

- Interpreter's perceived success of the consultation.
- Whether interpreters felt they faced any difficulties during the interaction and why.
- Whether interpreters felt they interpreted all the information accurately and why.
- If Interpreters did not translate verbatim then why they did not do this.
- What they had understood to be the main messages arising from the consultation.
- Interpreters' understandings of their roles during these interactions.
- Interpreters' relationships with their family/clients outside the consultation setting.

Questions in these interviews differed according to, whether I was interviewing a family/friend or a professional interpreter, their degree of involvement with the patient outside the consultation setting, and, in light of specific issues I observed during the consultation. An example of an interview schedule used with the interpreters is attached in the appendix 1d.

## **4.5 Bringing the interviews together**

I had expected that interviews with patients (both before and after their consultation), interpreters (when one was involved), and healthcare professionals would provide unique and diverse perspectives on the consultation interaction. By capturing such a range of views, I hoped to draw out comparisons between them, and explore the degree of congruence or discrepancy between what was said by the different parties. For instance, whether all the parties agreed about what the main messages arising from these consultations were, and whether they thought that effective communication had taken place or not. I also planned to compare and contrast these interviews to my consultation observations to see, amongst other things, the degree to which the perceptions of it matched up with what went on during the consultations. By doing this, I hoped to build up a detailed and multi-angled picture of the consultation interaction. The analysis of the interviews and observational data will be further discussed in a later section.

So far, I have described how the idea for this complex research design began to emerge and what I expected to achieve from it. In the following section, I will describe my experiences of carrying out this research design in practice and the decisions that I made in response to being faced with real challenges and practicalities.



## **4.6 Piloting consultation observations**

The purpose of the pilot exercise was to determine the logistics and practicalities of directly observing consultation interactions and, whether it was possible to be a discreet and unobtrusive observer. Before I undertook actual data collection, I used the health professional contacts that I had developed during a previous study to create an opportunity to observe six consultations with a dietician, and two with a DSN. I was given the opportunity to observe consecutive consultations all on the same day as part of one clinic. I observed only White patients, as the chances that these health professionals would consult with a Pakistani patient at the time of my visit were small, given that they only saw on average of two Pakistani patients per week. During these pilot observations, a new set of questions, to do with the practicality of being in the same room as the patient and provider arose. For instance, as well as watching the interaction, I intended to record it using a digital recorder, (more on this later) so I needed to decide where would be the best position for the recorder. I had also to decide how I would take notes discreetly whilst watching the interaction. I also found that there was a potential for both patients and health professionals to make eye contact with me during the encounter, and this exercise served as a good opportunity to find ways of sitting discreetly in the consulting room.

### **4.6.1 Consultations with stakeholders**

Observing these consultations and talking with the health professionals also gave me an indication of which types of consultations to observe and with whom. All patients with T2DM are asked to attend consultations to have their condition reviewed at either their local general practice, or at the hospital. Reviews can be yearly or more frequent, depending on the severity of the patient's condition. Since my concern was with how diabetes-related information is exchanged or communicated in consultations, it made sense to observe these reviews. I also consulted with stakeholders involved in the organisation, delivery and development of diabetes services to explore which consultations they thought it would be best to observe. Stakeholders, who I identified through discussions with my supervisors and through a public health consultant, Dr Margaret Douglas, who was also an advisor on this study, included a public health consultant, DSN, diabetes register facilitator, community pharmacist, secretary of the diabetes framework, a GP, and Pakistani patients with T2DM. Most were of the view that I should observe review appointments for the reasons I described above. In practice, I did observe a consultation with a GP, because his patient had invited me to observe it, since her diabetes would be discussed during the consultation. Some

stakeholders suggested that I limit my observations to the hospitals as dietician and DSN consultations could also be observed in conjunction with the doctor's consultation. Their argument was that the lengthier consultations with DSNs and dieticians would be a useful means to observe how a patient's life circumstances is discussed as these were more likely to be raised in such consultations. Patients suggested that I should observe reviews with the doctor as physical examinations took place (blood pressure and feet check etc) during them, and test results were discussed both of which were important factors to them.

I initially decided to observe a mixture of different types of consultations which were conducted as part of patients' diabetic review appointments both in general practice and in hospitals. However, as mentioned, I only got the opportunity to observe one general practice consultation and this was not a review appointment.

Patient interview schedules were piloted on several Pakistani people to determine whether the questions could be conveyed appropriately in Urdu and Punjabi while retaining the intended meaning. This included checking for literal translation but also to see if meanings in English such as 'satisfaction' (with consultations) could be back- translated to reflect the true meaning of the question. Back-translation is more rigorous when carried out by people other than the person who translated the documents in the first place. Words and concepts that were more difficult to interpret in Urdu and Punjabi were discussed to understand exactly what they were expressing and the equivalent expression in Urdu/ Punjabi was then agreed upon.

Despite this preparatory work, issues and challenges did arise during the actual data collection process which was not foreseen during the piloting exercise. I will now go on to describe my experiences of collecting the data, including recruitment of respondents.

## **4.7 Study sample**

During my consultation exercise with stakeholders, I also discussed the types of patients I should involve in my sample. It was suggested that I include newly diagnosed patients, as more information and education was likely to be delivered to them than to veteran patients. Other stakeholders were of the view that observing the quality of interaction between health professional and patient was most important, regardless of the time elapsed since patients' diagnosis and how established a relationship they had with their health professionals. Given that Pakistani patients constitute a small number of the patients seen by health care

professionals on a regular basis (as I established from the DSN and dietician whose consultations I sat in on), I was not optimistic about achieving the sample size I needed by restricting the criteria to include only newly diagnosed patients. Thus, in order to optimise my chances of achieving my sample, I decided to recruit patients regardless of when they were diagnosed with the condition. Coupled with the decision to target diabetic review consultations (be it at the hospitals or general practices), the inclusion criteria for the sample were as follows:

- Pakistani male or female with T2DM.
- Aged 18 or over.
- Patients who had a diabetes-related consultation due within two months of receiving an invitation letter.

At the outset, I intended to compile 16 cases studies. This would involve recruiting 16 patients, their health professionals and interpreters (when one was involved). This would have given me a sample of between 32 and 40 respondents. For a qualitative study this initially appeared to be a suitable sample size. However, in reality this was neither feasible nor practical as I will discuss when illustrating the size of the sample I actually achieved. Firstly, I will describe how I recruited the participants for this study.

## **4.8 Recruitment**

In practice, the recruitment pathways I used largely dictated what types of consultations I observed and in what setting. I observed one consultation in General Practice and the rest in two hospitals. Most of the hospital consultations were diabetic reviews delivered by seven consultants. Two consultations were with DSNs and two with dietitians. Two patients were both seen by a DSN and a dietitian during back-to-back appointments with them, so I observed two consultations each with the same patients.

Recruitment for this study was particularly complex and challenging. Not only was I recruiting patients but also their health professionals and interpreters. Moreover, I was asking them to partake in two different methods of data collection (observations and interviews). In order to recruit patients and their health professionals, two different strategies were used. Current literature (Greenhalgh, 1998), and previous experiences (Lawton et al. 2006a) of recruiting from within the South Asian community both indicate the need for several routes for maximising the chances of recruiting South Asian patients. In

some instances I was recruiting the health professionals before I recruited the Pakistani patient (the health services route). In other cases I recruited the patient first and then their healthcare professionals and interpreters (the community route). The two strategies are illustrated in figure 4.1.

#### **4.8.1 Community recruitment**

It is generally recognised that ethnic minority groups are under-represented in research due partly to the resistance on the part of researchers to recruit them (Muhib et al. 2001). Researchers who have attempted to recruit from within the South Asian have acknowledged the difficulties of doing so as these people may be more reluctant to take part in research studies compared with the general population (Hughes et al.1995). Community recruitment has been identified as an effective way of maximising ethnic minority recruitment (Lawton et al. 2006a; McLean and Campbell, 2003). As I had previous experience of successfully recruiting South Asian respondents from within the local community in Edinburgh, I was keen to use this strategy again. This involved seeking potential patient respondents through personal networks within the community and securing their consent and agreement to take part and for me to approach their health professionals. These personal networks consisted of family members who knew of people with T2DM within the community. Additionally the leaders of two local community groups were informally approached and asked if they were willing and in a position to refer any potential participants to myself. Only three patients were recruited in this way (one did not match the inclusion criteria). One of these patients had their reviews in General Practice and the other at a hospital. Part of the reason why I did not gain many respondents through the community was simply because, in the end, I did not need to use this recruitment strategy as most of my sample was quickly obtained through the health services route.

#### **4.8.2 Health services recruitment**

Most of the sample respondents were recruited into the study through the health services. As discussed earlier, I endeavoured to observe diabetic-related consultations which can be held at either general practices or hospitals, hence I targeted both of these health care facilities.

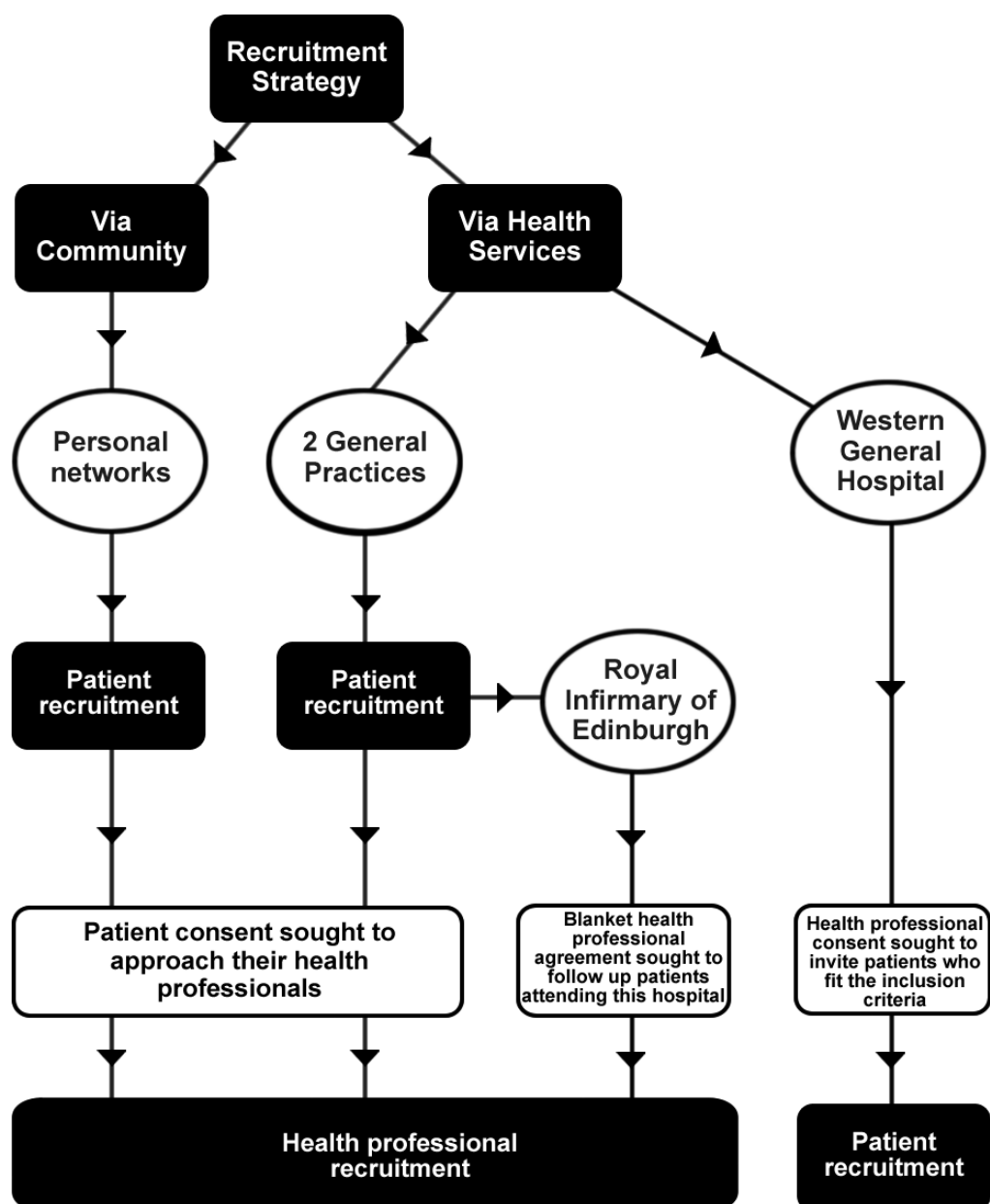


Figure 4.1: Recruitment methods for patients and their health professionals

#### (1) General practice

Permission was sought from the Lead GP for diabetes of two General Practices in Lothian (which had a reasonably high percentage of Pakistani patients with T2DM) for invitation letters to be sent out to patients registered at their practice. These letters together with information sheets and opt-in forms (examples of which can be found in the appendix) were sent out by the practice on paper headed with the practice details and signed by the lead GPs endorsing their involvement with the study. As well as being sent out in English, all this

material was translated by me into Urdu, and sent out as part of the package. Potential participants then contacted me directly, indicating their interest in taking part by either by filling in and posting back an opt-in form, or by telephoning me. It was originally planned that patients opting in this way would subsequently be asked if I could approach the health professionals they were due to see for their T2DM. Eleven respondents opted into my study this way, but only one patient had an upcoming consultation at their general practice. Most of the other patients were due to have their diabetic review consultations at hospital. Other patients had recently had their review appointments and were not due for their next one for at least another six months. The one patient who had their consultation in general practice agreed to their GP being approached and hence I was able to observe one consultation in general practice.

## (2) Royal Infirmary of Edinburgh (RIE)

Most of the patients opting in from general practices had their diabetes appointments at the RIE. This initially created a problem for me, as most of my contacts with health professionals were established in the Western General Hospital, and I had not envisaged that the RIE would be one of my research locations. I realised that I required access to this hospital or I risked losing many potential participants. A Public health consultant (one of the stakeholders I met with) put me in touch with the lead clinician at the metabolic unit. He sent a memo around to all the staff informing them of my research and making them aware that I wanted to observe some consultations there. This was in order to seek blanket agreement for my research to go ahead at the hospital and to give those health professionals who may object to taking part an opportunity to opt-out of the study. In practice, none of the health professionals from the RIE refused to take part.

## (3) Western General Hospital (WGH)

At the same time as the general practice recruitment, I approached consultants at the Western General Hospital (WGH) in Lothian inviting them to take part in my study. This hospital was chosen due to established links with key members of staff. The majority of consultants agreed to take part. A DSN at the WGH together with secretarial staff identified Pakistani patients with T2DM due for consultations with these consultants, and sent out invitation letters (similar to those sent out by the general practices and signed by a consultant). Again, potential participants contacted me, and as their health professionals had already consented

to take part in my study, all I needed to do was to inform the reception staff at the hospital when and with whom I would be attending.

The number of invitation letters sent out and responses received are illustrated in the flow chart on the next page.

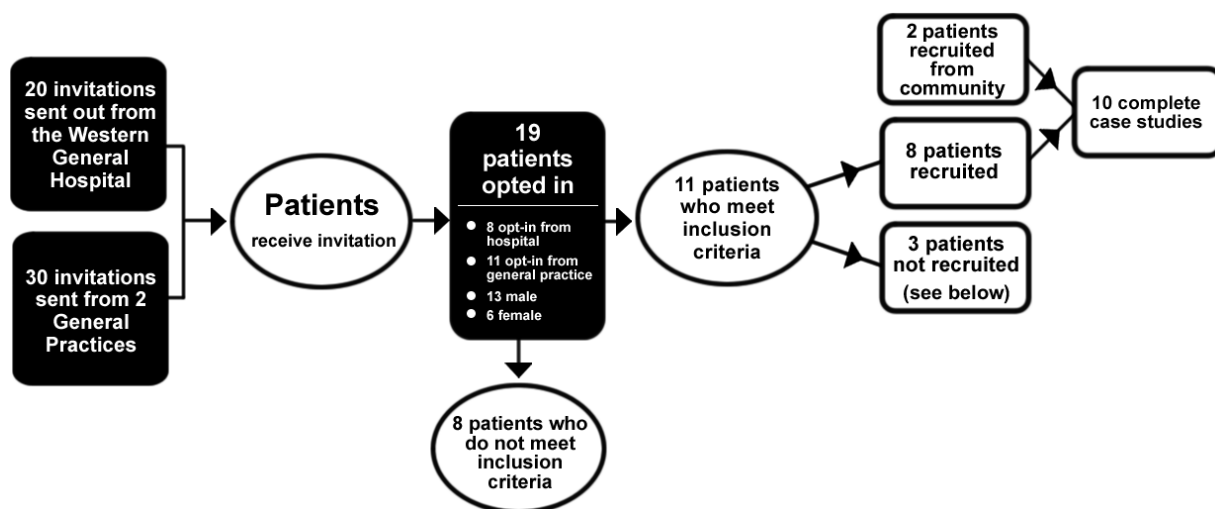


Figure 4.2: Patient recruitment - invitations and responses

Nineteen patients opted into the study, a reasonably high opt-in rate given the well known fact that Pakistani people are difficult to recruit into research studies, and especially considering that I was asking a lot from these people. This may have been partly due to the translated information and invitation letters that were sent to these patients. As mentioned, I translated all the material myself and I ensured that the language used in them was simple and easy to read. I will reflect more on this in a later section.

Three patients could not be included in the sample for logistical reasons such as there being a significant overlap in the timings of their consultations and those I had already arranged to observe. Co-ordinating pre- and post-consultation interviews around the date and time of the appointment required a great deal of forward planning and flexibility. The practical constraints of doing this type of research together with the intensive labour required to translate all the non-English data into English exceeded my original expectations and forced me to revise my original intentions. Moreover, each case study yielded substantial amounts of data and had I chosen to stay with my original plan of collecting 16 case studies, I would have ended up with an insurmountable amount of data which would be difficult to analyse

thoroughly. Hence, I stopped collecting data after the completion of 10 case studies. Also at this point in data collection I had identified many cross-cutting findings and themes and I felt that I had sufficient data to address the study aims. The type of data gathered for all 10 cases is detailed in Table 4.1.

Since I observed two back- to-back DSN/dietitian consultations with the two patients, the healthcare professional interviews and consultation observations totalled 12 each.

The case studies collected were wide-ranging and diverse in terms of the sample characteristics such as gender, age and patient's fluency in English amongst other things. I purposively sampled to obtain this diversity. I ensured that I included roughly equal numbers of male and female patients. Most consultations were diabetic reviews appointments at hospitals in which patients' diabetes management was monitored through a series of blood tests, blood pressure check, feet and (sometimes eye) examinations and questions about diet and exercise. Some cases included separate sessions with dietitians and DSNs. I observed only one consultation in general practice which was dissimilar to the diabetic reviews I observed at the hospitals. The GP consultation involved discussion of diabetes and other health-related problems while, in the hospital only the patient's diabetes was discussed. Insulin-treated patients tend to be referred to, and reviewed in hospital so five patients in my sample who were on insulin and, one was due to begin, had their consultations in the hospitals. Some details of each of the 10 case studies are provided in Table 4.2.

In my patient sample, nine were immigrant Pakistanis and one was a British born Pakistani. Seven of the patients were aged 56 or below and most were dealing with other illnesses as well as diabetes. The nine immigrant patients spoke Punjabi (and in one case Urdu) as their first language. Seven patients spoke limited English, and three patients spoke fluent/good English. One of these patients had migrated from Kenya and spoke both Punjabi and English equally well.



Table 4.1: Data collected for all case studies.

Interviews and consultation observations	Number
Patient pre-consultation interviews	10
Patient post-consultation interviews	10
Health care professional interviews	12
Interpreter interviews	3
Consultation observations	12
<b>Total interviews</b>	<b>35</b>
<b>Total observations</b>	<b>12</b>

### 4.8.3 Recruitment of interpreters

Three interpreters took part in this study. One interpreter was recruited through personal contacts. She then put me in touch with the patient (also her friend) she was interpreting for. The other two were professional interpreters who worked for an interpreting agency. To recruit these interpreters, I contacted the manager at the interpreting agency who asked one of the health professionals at the hospital (where the consultations were due) to confirm the details of the consultation together with the patient's name. Once confirmation was received, the manager checked who would be available to interpret on the day of these consultations and forwarded information about my study to these two interpreters together with consent forms. I was verbally told by the manager that both interpreters had agreed to take part and I could obtain written consent on the day of the consultation.

## 4.9 Ethical considerations

Ethical approval for this study was obtained from Lothian Research Ethics Committee (LREC) (date of application: 27 March 2006; date of approval: 12th May 2006; LREC ref: 06/S1103/17). I was also required to secure research and development approval which involved obtaining an honorary contract together with enhanced disclosure. The process of

gaining ethical approval proved to be very useful as it provided a systematic and logical framework in which research issues such as access, recruitment, sampling and location of research and so on could be developed and worked through. The process of completing the application form and compiling the relevant documents (such as invitation letters and information sheets) highlighted some ethical challenges and issues which required consideration when conducting this type of research.

I will first outline some of the ethical concerns to do with the recruitment of my Pakistani sample for this study. As I belonged to the relatively small and close-knit Pakistani community in Edinburgh there was a fair chance of my knowing some of the patients receiving an invitation to take part in the study. Ethically speaking this could compromise confidentiality, so to address this issue, I decided to discourage such patients from taking part on the basis that it would be difficult to be impartial and remain professional. In practice this did not happen and the people who I did recruit through personal contacts were unknown to me.

#### **4.10 Informed consent**

Written consent was obtained from all the patients, health professionals and interpreters taking part in the study. In all cases patient consent was taken before their pre-consultation interviews. As two of the patients could not read either English or Urdu I explained the content of the consent form in person.

#### **4.11 Translating patient information material into Urdu**

I translated all the English invitation letters and information sheets into Urdu so that each patient received material in Urdu as well as English. This proved to be a time-consuming and sometimes difficult undertaking. As ethical consent had been sought prior to the material being translated I was required to accurately translate the English documents into Urdu making sure that no meaning was changed. To check the accuracy of the translated material, I back translated the Urdu material into English. Some of the difficulties lay with trying to find the equivalent words and sentences in Urdu to convey accurately what was being said in English and in plain Urdu.

Table 4.2: Some characteristics of the 10 cases.

	Pseudonyms	Gender	Age	Recruitment	Place of Consultation	Health professional(s) involved	Interpreter present	Medication
CS1	Mrs Nargis	Female	50's	Community	General Practice	GP	No	Tablets
CS2	Mrs Salma	Female	40's	Community	Hospital RIE	DSN + Dietician	Yes, friend/client	Insulin
CS3	Mr Javaid	Male	60's	Opt-in	Hospital WGH	Consultant	No	Tablets
CS4	Mr Khan	Male	80's	Opt-in	Hospital WGH	Consultant	No	Tablets
CS5	Mr Ibrar	Male	50's	Opt-in	Hospital RIE	Consultant	No	Insulin + Tablets
CS6	Mrs Amna	Female	50's	Opt-in	Hospital RIE	Consultant	No	Insulin
CS7	Mr Mirza	Male	50's	Opt-in	Hospital WGH	Consultant	No	Insulin
CS8	Mrs Naseem	Female	60's	Opt-in	Hospital WGH	Consultant	No	Insulin
CS9	Mr Shabir	Male	40's	Opt-in	Hospital WGH	Consultant	Yes, professional	Tablets
CS10	Mr Raza	Male	40's	Opt-in	Hospital WGH	DSN + Dietician	Yes, Professional	Tablets

CS = Case Study

DSN = Diabetes Specialist Nurse

In my (and others') experience of reading translated Urdu materials, I have noted there is a use of complex sentences and difficult words that are incomprehensible to lay readers.

Hence, I wanted to ensure that the language I used was simple and easy to follow, particularly for those patients who had received limited formal education. I drew upon the

wisdom of family members and other resources such as Urdu dictionaries and material that I had previously translated for another study to compile these documents. Four people read my first drafts and all of them said the translated material was 'fine'. I got the impression that this was partly because people were used to badly translated material, but also because they found it difficult to offer any critical commentary. I discovered that if I read the documents out aloud, people became much more engaged and began offering me suggestions for making changes.

#### **4.12 Assessment of patients' English language skills**

The 10 patients who took part in the study had varying degrees of English language skills. At one end of the spectrum was Mr Khan who spoke very little English and displayed limited English comprehension. At the other end, was Mr Mirza, who was born and raised in the UK and spoke fluent English. I did not assess patients' English language skills by any objective means but relied on my judgement which was informed by a number of factors during the fieldwork stage. My initial impressions of patients' language skills were formed by my visits to patients' homes for the purposes of their pre-consultation interviews. My interviews with the patients afforded me the opportunity to ask patients about: how fluent they thought their English was; whether they thought they needed an interpreter and their level of education. Coupled with the information gathered through these interviews, on some occasions I was able to listen to patients talk in English to members of their family and on some occasions they would say something to me in English which gave me an indication of their fluency. For example Mrs Nargis' spoke fluent English with her grandchild and Mr Khan spoke to me in (broken) English to illustrate how he would talk with his health professional. My judgements of patients' language skills were informed by my own personal experiences of being part of the Pakistani community, in which many members have a varied range of competency in English.

Patients' English language skills became more clear when I observed them talking with, and listening to, their healthcare professionals. I judged patients language skills upon their comprehension of what the healthcare professional said to them, the quality of their answers to the healthcare professionals and of the questions they raised in their consultations. I observed patients attending without interpreters and really struggling to understand what their health professionals said to them and some also struggled to get their points across to them. Although Mrs Nargis spoke very little during her consultation, her responses to the

GPs questions which were quick and accurate, in terms of the answers she provided, reinforced my initial impressions that she was competent in her English language skills.

#### **4.13 Transcription**

All Punjabi and Urdu recordings were translated and transcribed by me into English. The remainder of the interviews and consultation recordings were transcribed by experienced transcribers, and the transcripts checked by me for accuracy. Preparing typed transcripts for all translated recordings took a considerable amount of time and effort, particularly as it is sometimes challenging to find the equivalent term in English and vice versa. It was also impossible to translate verbatim due to the differences in sentence structure and grammar between Urdu/Punjabi and English. Translating conversations as opposed to documents can never be entirely objective as judgements have to be made on how and what to translate in order to ensure as accurate a transcript as possible. My preferred way of transcribing is translating sentence for sentence of the conversation. One transcriber who helped me did it differently in that she summarised whole chunks of conversation. I found that this made it difficult to listen to the recording while following the transcripts as sentences were not in order and sometimes verbal pauses important to the conversation were omitted. I addressed this issue by giving the transcriber an example of a transcript I had transcribed and demonstrated how I preferred interviews to be transcribed.

Non-verbal behaviours and actions that I had recorded in my fieldwork notes whilst observing the consultations were included in the transcripts to complement the verbal data. For example if respondents facial expressions and/or body language was considered significant to the conversational exchange being transcribed then a description of these non-verbal gestures would be added in brackets immediately after this conversational exchange. Similarly, a brief description of any physical examination (s) taking place would also be described within the transcript in order to provide important contextual information to the dialogue between patients, providers and in some cases interpreters.

#### **4.14 Observing the actual consultations**

Most of the diabetes consultations I observed were part of a regular clinic that patients attended every few months, depending on the severity of their condition and their management regimen. Thus, it was important to bear in mind that the consultations I was observing were a segment of a series of past and future consultations. Silverman importantly

points out that this type of observation and *“Its focus on the present may blind the observer to important events that occurred before his [sic] entry on the scene”* (Silverman, 1993 page 49). For instance, some of the consultations I observed consisted of an established health professional- patient relationship and sometimes discussions that took place in previous consultations were addressed or continued. Thus, the historical context of these consultations needed to be explored (through interviews) to gain a better understanding of the interaction I had observed.

Consultations were usually observed as part of a diabetes clinic during which doctors saw several patients one after the other. Since I was observing specific consultations (usually one during a given clinic), which (in most cases) were in between other consultations, it was necessary to keep my interference to a minimum and reduce any disruption to the running of the clinic. When health professionals came to the waiting area to call their patients, I followed the patient into the consulting room rather than go in before them so that any rapport between health professional and patient was not hindered by me walking between them. Once in the consulting room I introduced myself to the health professional (particularly if they did not know me) even though most of the health professionals had agreed to take part beforehand. This served as a good opportunity to ask them to sign the consent form whilst I set up my recording equipment and found an extra chair. As soon as the form was signed I would move away and seat myself, after which the consultation began.

#### **4.14.1 Field notes while observing**

Before the consultations began I asked if anyone had any objections to me taking notes during the consultation. No one objected. I took notes in a notepad which I had purposively chosen to be small so that little attention was drawn to me during the consultation. I wrote down descriptions of non-verbal behaviours and actions such as hand gestures, facial expressions, respondents' appearances, details of any physical examinations that were carried out, the layout of the room, where and how people were seated. I also included the manner in which respondents engaged with each other; for example, whether they appeared relaxed or nervous, how and with whom eye contact was made. I noted how much time health professionals spent typing into computers and reading the patient's medical notes. Moreover, as I was part of the research setting, I noted down how I perceived the atmosphere to be and my reflections upon the interaction. There were some occasions when I was drawn into the interaction and I noted how respondents attempted to engage with me which was usually through direct eye contact and questions posed to me. In these instances, I also

recorded how I felt my presence had changed the dynamics and potentially the outcome of the consultation. When transcribing the audio-recordings, I added in the additional detail that was not picked up by the recording such as the non-verbal behaviours and actions. Since the consultations were audio-taped I was able to add in the additional detail that I had

#### **4.14.2 What to observe in the consultation**

A key consideration for me was what I actually needed to observe during these consultations. Ethnomethodologists search for the *processes* by which people make sense of interactions, events and society (Stake, 1995). This approach is based upon the assumption that actions and interactions have social meanings for participants, and that people assume that others share the same meanings. While I was interested in studying the social processes upon which the doctor-patient interaction is predicated, my interest also lay in how and why ‘communication’ was established (or not as the case may be) in these encounters. For instance, I anticipated observing things such as, how patients made themselves understood or what health professionals said in their ‘opening line’ to mark the beginning of the consultation. Also, how the main messages were conveyed by the health professional and how and when patients chose to talk about any concerns they had. The quality of ‘communication’ and within that the language used and how people listened to each other were also features which I explored.

Pre-consultation interviews with the patient gave me some ideas and assumptions about the prospective consultation together with knowledge of the patient’s perspective of what to expect. It is important to acknowledge that these pre-consultation interviews partly influenced what ‘I looked out for’ in my consultation observations. In some instances, where the patient’s English was not good I had an understanding of what they were ‘struggling’ to say to the doctor by virtue of my interview with them. This was advantageous as instead of spending time trying to understand what the patient was trying to convey (as the health professional had to do) I could focus my attention on how the patient was conveying their concerns and how the health professional was receiving what the patient was saying. On the other hand, my familiarity with the patient meant that sometimes I found myself more inclined to closely observe the health professional in an attempt to understand their agenda and expectations particularly as I had not interviewed them beforehand.

#### **4.14.3 Audio recording the consultation**

Recording the conversation was essential as the recording contained more material than I could ever possibly write down. Furthermore, the material collected by the audio-tape would essentially be ‘uncontaminated’ and not subjected to the researcher’s preferential tendencies, as Bowling (1997) describes:

*“Selective auditory perception also operates to lead listeners to be most likely to hear sounds that correspond to the sounds of their own language or the language system of the observer...hence the popularity of using audio recordings” (p.319)*

The recordings were essential in yielding written transcripts of everything that was said. This later formed the core of the analysis and something my notes would have been unable to capture. Now I will provide a rationale for why I chose to audio-record and not video-tape the consultation. In so doing, I will provide further justification for my decision to observe the consultations in person.

#### **4.14.4 Video or audio recording the consultation**

Clinical encounters between patients and their health professional are commonly recorded using video or audio technologies for later analysis (Bowling, 1997). Fewer studies have involved direct observation by the researcher (McCourt, 2006) as the researcher’s presence in the consultation arena has tended to be substituted by either a video camera or tape-recorder. Other studies employing direct observation have not made use of recording devices (Somerville et al, 2008), thus relying heavily on researchers’ fieldnotes. Studies reporting direct observation coupled with audio-taping have given precedence to data derived from the audio-taping, as analysis of such data can be undertaken in a more systematic manner, with observations providing useful contextual and background information. It appears, on the whole, that research into healthcare consultations has taken advantage of recording technologies. The following paragraphs provide examples of studies which have chosen to use either audio-taping or video-taping to record the consultation together with advantages and disadvantages of using either technique.

In a study by Barry et al. (2000), consultations between GPs and patients were audio-taped. The data collected in this way yielded a number of useful insights when complemented by the semi-structured interviews with patients undertaken before and after the consultation. However, significant non-verbal behaviour which could not be captured on audio-tape was



potentially lost. For example, a doctor participating in Barry et al's (2000) study revealed (during a post-consultation interview) how she felt pressurised consulting with a patient who chose to remain standing for the duration of the consultation, and who she described as being a "*biggish sort of...brashish South African*". The researchers did detect a slight strangeness about the encounter when analysing the verbatim transcript but, had the doctor not disclosed this potentially vital piece of information, this would have remained invisible to them and perhaps altered how the data were interpreted. Furthermore, the researchers were relying on participant's perceptions of 'significant' non-verbal cues which risked eliminating other equally vital embodied aspects of the interaction. Key non-verbal behaviour which might have affected the dynamics may well have been missed, including silences during the interaction which are difficult to account for using the audio-recording alone.

This issue can potentially be addressed through the use of video recordings (Ford et al., 2006). Ruusuvuori (2001) analysed video-recordings of 35 doctor-patient encounters in Finnish primary care. The author discovered, through examining this visual material that, when doctors disengaged from the interaction and engaged in studying the medical notes, patients appeared confused about whether the doctor was listening or not. The 'direction of gaze' and the way doctors positioned themselves relative to the patient was found to be a significant factor in determining the fluency of conversation and successful rapport between the two parties. Ruusuvuori (2001) points out that studying the co-ordination of verbal and non-verbal aspects in medical interactions may enhance our understandings of how power relations and passivity are enacted. Arguably, video-recording could be considered the solution to how we capture this phenomenon in its entirety as we can 'see' as well as 'hear' the event within its social context.

The use of video technology, however, does have its disadvantages. There are two types of concerns, one to do with the social sensitivity of such devices and the second to do with the practical and logistical implications of using video technology. Video-recording in public spheres is considered problematic due to the intrusiveness of having a camera pointing at, and recording what people say and do (Bowling, 1997). Participants can find the camera disconcerting and may react differently in its gaze to how they would in the absence of the camera, an issue which resonates with the 'Hawthorne effect' described earlier. Furthermore, some Muslims strongly object to being video-taped due to their religious beliefs and practices. Although Islamic practices vary across the world, some Muslims

consider taking any kind of photography as *haram*<sup>1</sup> (not permissible) particularly when women are involved. This is in keeping with the practice of *Purdah*<sup>2</sup> which does not permit men (especially strangers) to see women (Shaw, 2000).

A further, more pragmatic concern is to do with where the camera is positioned. The camera assumes a particular angle on the consultation and is susceptible to omitting potentially vital non-verbal behaviours due to the static nature of such technology. Also, setting up camera equipment can be cumbersome and requires the camera to be located in a position that will capture the most detail. This can be difficult in a small room and, depending on the angle of the camera, there is a risk that one person might not be captured as prominently in the frame of the camera as another. Ruusuvaori (2001), for example, described findings which appear biased towards reporting the doctor's rather than the patient's position and non-verbal behaviours, suggesting the camera may have been positioned to selectively record the doctor and his or her activities. Furthermore, participants may alter their positions in the room and move out of the frame of the camera altogether, causing the loss of vital (non-verbal) data.

Tape-recording by comparison is less obtrusive, and a tape recorder is an easier piece of equipment to manage. Digital audio recorders can be small and inconspicuous, and can be placed anywhere in the room, even out of the sight of the participants, so they are less conscious of the recording device. The digital recorder takes, literally, five seconds to set up. The use of a tape-recorder can be considered a more comprehensive and egalitarian tool for data collection than video-recording, as all the speakers are captured equally and, unlike the video camera, it does not favour a particular angle at the risk of losing other angles. In weighing up the advantages and disadvantages of the different recording equipments that I could potentially use, I decided to use a digital audio recorder for my study as it offered me flexibility and simplicity.

A practical reason also contributed to my decision to observe rather than just record the consultations. Before I began my fieldwork I thought there might be a possibility that health professionals would prefer to be interviewed immediately after the consultation rather than arranging a later date and time out of their busy schedules. Had such an opportunity arisen I would have needed to know what occurred in the consultation so that I could base my

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<sup>1</sup> Unlawful in the context of Islamic practice (Shaw, 2000)

<sup>2</sup> Literally means 'curtain' and is usually described as a system of segregating unrelated men and women from puberty. *Purdah* is more than a system of screening women from men, it is also a moral code that governs relationships between the sexes.

questions around the actual event. In practice however all the health professionals were consulting with patients immediately after all the ones I observed so there was no opportunity to interview them immediately after.

## **4.15 Reactive effects**

### **4.15.1 Digital audio-recorder**

Research participants who are aware that what they are saying is being recorded are likely to react differently (Robson, 1993), resonating with what I said earlier about the 'Hawthorne Effect'. There is speculation that participants may 'perform' for the recorder and not be entirely honest in their actions or words (Bowling, 1997). However, Robson (1993) argues that the obtrusive effect of using such devices is unknown as the effect of not having the device on participants would need to be investigated in order to support this claim. However, it is often speculated, that respondents quickly forget the recorder is turned on and the reactive effects are believed to be minimal (Robson 1993; Bowling 1997). As the digital recorder I used was discreet, respondents barely looked at it during the consultations and interviews (when these were conducted face-to-face). During the consultations I felt my presence perhaps negated any reactive effects the digital recorder may have had.

### **4.15.2 Researcher as observer**

One of the major critiques of observation is the reactive effect of the researcher upon the participants which challenges the rigour of such research (Flick, 1998). Jorgensen (1989) describes strategies used to minimise such 'observer effects' by essentially limiting interaction with those observed. Minimal interaction can be achieved by avoiding eye contact, and through the use of simple behavioural techniques such as not re-enforcing attempts at interaction from the observed and planning one's position in the research setting so that one is 'out of the way'.

In this study, I usually sat in a position that enabled me to observe the profiles of both the health professional and patient. This also meant that I was not in the direct line of sight of either party which also signalled that I was 'outside' of the interaction. However, in some cases, my choice of possible positions was limited particularly in consultations involving interpreters. For example, during one encounter the room was very small with a large desk in it. The doctor sat across the desk directly opposite the patient and the interpreter. The

only space for another chair was behind the interpreter and the patient which meant (for the most part) I was observing their backs. However, this did not stop the patient from turning around and attempting to engage me in the conversation that was taking place at the time. I found that in some cases that avoiding eye contact (by looking at my notepad) helped to discourage patients from talking to me. Moreover, as mentioned earlier, emphasising my role as a non-participant observer before the consultation helped to keep my involvement to a minimum in some cases at least.

In most consultations, I was able to successfully execute my role as a non-participant observer; however there were occasions during other consultations when this was difficult. One example was during an interaction between a doctor and a male patient in his eighties, which is reported in the following chapter. The patient's first language was Punjabi. He barely spoke any English but was not accompanied by an interpreter. The doctor spoke English with an Irish accent. During the consultation both the patient and doctor struggled to understand each other. As the consultation continued the situation became increasingly awkward and the patient began asking me to translate what the doctor was saying to him. I initially insisted that he continue speaking without my help, but eventually I had to assist as communication between the doctor and patient had severely broken down.

Another, less extreme example, took place during a consultation involving an interpreter in which the patient was struggling to provide the names of the medication he was taking for his diabetes. The patient recalled that during my pre-consultation interview with him he had shown me his medication and so asked me to provide this information to the doctor. I remained silent and looked at my notepad which reminded the patient that I was not to interfere and hence he continued the conversation without my help.

The examples presented above are some of the ways in which my presence influenced some of the consultation interaction in an overt way. It appeared that patients' awareness of my presence in the room became heightened when they experienced difficulties and needed help. However, I also felt that patients were confident to ask for my help because I had established a rapport with them during the pre-consultation interviews but also possible because they did not quite understand my research. In these interviews they discussed their illness with me together with what they planned to talk about it in their prospective consultations. Perhaps patients sought an easier solution by asking me rather than 'making the effort' in attempting to resolve the situation themselves. Indeed, one of the doctors in the study said his patient

was being 'lazy' during the consultation I observed, as he felt the patient was relying on me to interpret for him. I will further discuss these matters in the findings and discussion chapters.

As in the above section, I will now provide some reflections upon my experiences of conducting the research for this study.

#### **4.15.3 Interviewing participants**

A key assumption underpinning this study is that it is possible to learn about patients', health professionals' and interpreters' perceptions and experiences of diabetes consultations. Semi-structured interviews offered insight into individual thinking that, in Goffman's (1959) terms, is articulated 'behind the scenes'. In other words observing the consultation was significant in seeing how people 'performed' or 'acted', but interviews were intended to expose what individuals made of these interactions when asked to reflect upon them. As mentioned in an earlier section, semi-structured interviews were an ideal way of achieving the appropriate balance between keeping the conversation fairly focussed upon the consultative process and also allowing the participant to raise and discuss issues which they felt were important and relevant to the topic of conversation.

Patient interviews took place in their homes and lasted between 40 minutes and one and a half hours. Health professional and interpreter interviews were conducted over the phone and lasted between 10 and 30 minutes. Health professionals seemed to prefer phone interviews as these were quicker and more convenient for them to do. When I asked some of the health professionals when I could return to interview them they would hesitate but when I offered the option of a phone interview they normally immediately agreed. I used a telephone recording device together with a digital recorder to record these interviews. All respondents were asked for their permission to record their interviews and consent was given by all except one patient who refused to be recorded both during his interviews and consultation.

Despite my repeated attempts at explaining to patients the purpose of my research and my role within this study, there were occasions when it appeared that I was misperceived as a professional interpreter, or community group member, or health professional. In one instance a patient asked me to prescribe them a medication that would ease their symptoms, in another I was interviewing a patient when her friend turned up and I was introduced as the

interpreter. Part of the reason for these misconceptions may have resulted from the ways these patients understood what 'research' meant. It was sometimes difficult for me to explain my research aims particularly as these patients were not gaining any direct benefit from taking part. I perceived that some patients would 'pretend' to understand why I was there just to be polite. Conversely, educated patients appeared to better understand the research although sometimes they too questioned why I was giving up my 'precious' time to visit them in their homes.

The above issues highlight the complexities of doing qualitative research within this kind of community, particularly in a research culture where informed consent is compulsory. Although patients signed a form reflecting 'informed' consent the reality was that some of these patients struggled to understand my research and my role as a researcher.

#### **4.15.4 Building Rapport**

Cornwell (1984) carried out a study of people's attitudes to health, illness and medical care using semi-structured interviewing. She found that, at the beginning of the study, respondents provided her with their 'public accounts' and it was not until they were interviewed several times, that respondents became familiar with her, and began revealing their true feelings and as Cornwell puts it 'their private accounts'. Cornwell (1984) highlights how the greater involvement and participation of the interviewer in the interaction aims to promote greater depth. The assumption made is that, once the level of communication has reached this 'depth', respondents' will reveal their 'true' feelings (Cornwell, 1984). During my own research I also found it to be very important to build up a good rapport between myself and my interviewees. Moreover, I found that having a degree of commonality with the patients was conducive to rapport building. My Pakistani ethnicity was advantageous in establishing and maintaining rapport as there was an assumption of some kind of shared understanding between the patient and me particularly around cultural and religious aspects. For instance, patients frequently made religious remarks during interviews because they assumed I understood the connotations associated with these remarks. Our commonality meant that to a large extent we shared tacit knowledge which facilitated and accelerated the building of my relationship with patients as I could reciprocate with the language they used. Nevertheless, this shared understanding could sometimes hinder patients from providing me with explanations of the kind of things that informed their beliefs and ideas. For instance, I once asked a female patient to explain to me why she perceived reading the Quran (Islamic holy book) beneficial to her condition. She appeared

confused and slightly offended at my question as I shared her religion and hence she naturally assumed that I would know the answer to this question. I addressed this issue by explaining to her that even if I knew what she meant it would be helpful if she could provide more detail for the benefit of those who did not hold this knowledge.

In the next and final section of this chapter, I will discuss the case study approach I used to organise the data and inform my analysis.

#### 4.16 The case study approach

As the research design consisted of multiple components, there had to be a way of organising and executing the multi-method approach in a systematic manner. Cases were organised around each Pakistani patient with T2DM who took part in the study. Before defining what a case study is, the following diagram helps illustrate what constituted a typical case study:

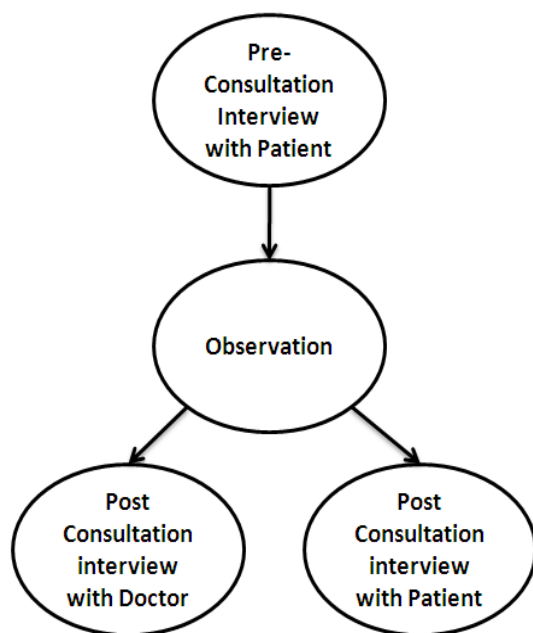


Figure 4.3: Components comprising a typical case study.

As can be seen from the above diagram a *case study* encompassed several different components. The primary interest of this study was to gain insight into diabetes consultations involving a sample of Pakistani patients. The multi-component element of these case studies arose out of the decision to explore more than just the interactions within these consultations. Complementary interviews were used to understand the experiences and

views of those involved in the consultation, and within the same case study there was more than one interview and sometimes even more than one observation. Since I had a sample of 10 patients this meant that multiple case studies were compiled. I will discuss the different components comprising a case study in a later section. Firstly, some of the theoretical and practical issues of the case study approach will be discussed.

#### **4.16.1 What is a case study?**

The case is an “empirical inquiry that investigates a contemporary phenomenon in its real-life context” (Yin, 1994). The ‘contemporary phenomenon’ can be virtually anything which can be studied in extensive detail using multiple sources of evidence, with data needing to converge in a triangulating fashion (Eisenhardt, 1989). Stake (1995) describes a case to be one among others, with the researcher concentrating their enquiry into this single case to help us achieve a detailed understanding which may have implications for other similar cases. For instance, a case can be an organisation or an institution such as a hospital, or an individual student within a classroom setting. Stake explains the case as being a “bounded system”, the periphery of which is recognised by the features that lie inside and outside the system. As the next section will illustrate, the study of the case is a debated matter. This debate or choice of conceptual methods, has implications for the subsequent analytical framework, however, in practice researchers are essentially doing the same thing, investigating the bounded phenomenon (the case) regardless of which stance they choose to take.

#### **4.16.2 The case: A method or object of enquiry?**

Yin (1994) defines the case study as a ‘*research strategy comprising an all-encompassing method*’. He considers the case study to be a methodological choice which he regards as being on a par with other methods used in social science research, such as surveys and qualitative interviewing. For Yin (1994), the case is inclusive of everything from the object of enquiry, the research questions, the analytical framework and the data collection methods. Notably, Yin (1994) sees the data collection methods as a component contained within the whole case study. This is not, however, a view shared by all researchers. Stake (1995), understands the case to be an object rather than a method. It is defined by virtue of the interest in individual cases and not by the methods of enquiry used. In this study, the ‘object’ of enquiry is the consultation and whatever else that is deemed relevant to the study



of this. The way in which the case is obtained and examined is considered external to the case itself. In other words the methods lie outside the case.

My position lies more with Stake's view and I perceive the case to be an 'object' to be studied and the methods as the resources to obtain and assemble each case. In this way, alternative methods (other than those used in the study) could potentially be used to assemble case studies with similar components. For instance, the administration of standardised questionnaires could replace the use of interviews, although the type of data yielded would be different. The point to be made here is that essentially it is the object of enquiry that defines the case. The 'all inclusive' perspective held by Yin, does not account for what happens to the methods at the analysis stage which is why it made sense for me to segregate *the case* from the methods at the outset of the study, as Stake suggests. Figure 4.4 provides a visual illustration of the way the case was conceptualised for the purposes of this study.

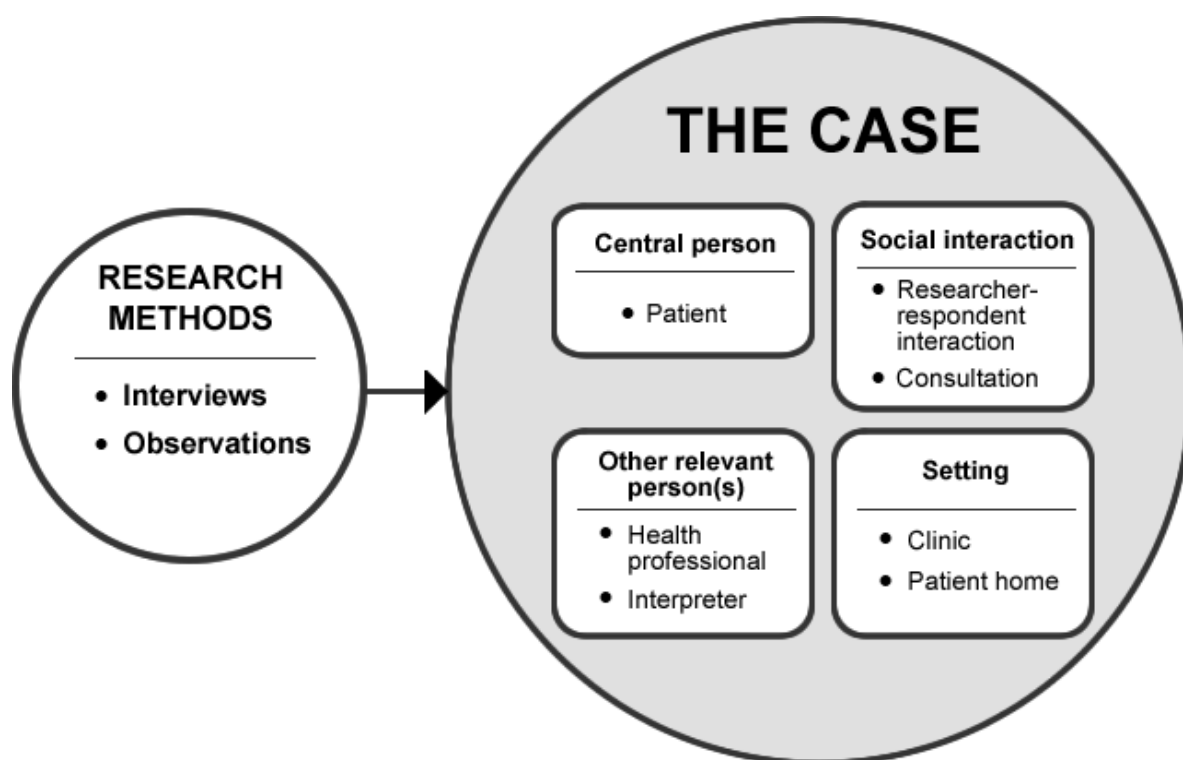


Figure 4.4: The case study framework used for this study

A case consisted of one central person (the patient), other relevant persons (health professional/interpreter), the setting (clinic/patient home) and the social interaction (consultations), all studied in a given timeframe.

#### 4.16.3 The purpose of the case study approach

Case studies offered flexibility as they could be broadened to include exploration of aspects outside of the consultation setting itself. They permitted a coherent and logical way of systematically organising this complex, often over-lapping and extensive data as each case could be managed as a separate unit. Figure 4.5 provides an illustration of a typical timeline of when interview and observations were undertaken to compile and complete individual case studies. Most case studies were compiled within a week with others taking longer to complete if health professionals were very busy and difficult to contact.

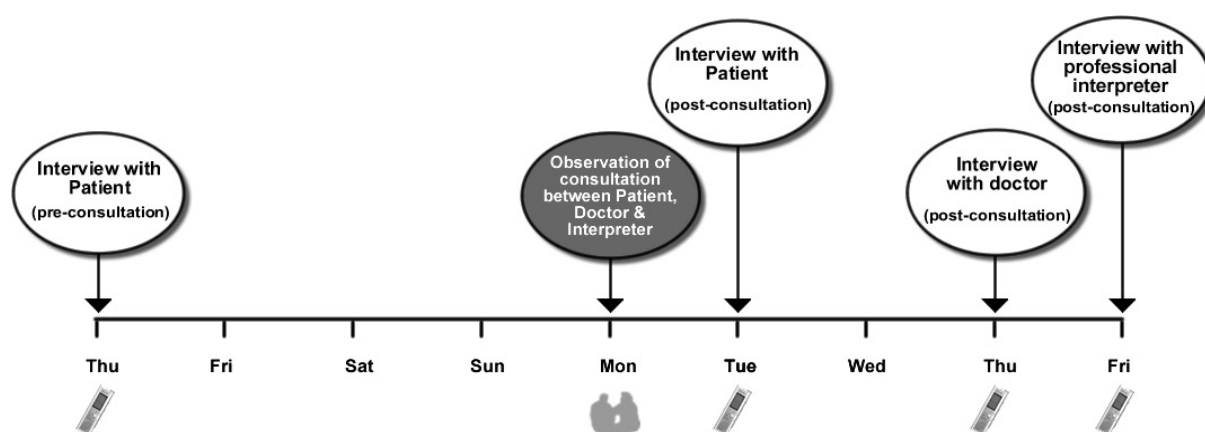


Figure 4.5: Case study example of when and how data was collected.

#### 4.16.4 Number of cases

Case study research requires that the numbers of cases studied are necessarily small, as they are intensively explored (Stake, 1995). However one of the common criticisms of a small sample is that it is unlikely to be a strong basis for generalisation. Stake argues that the purpose of doing case study research is not to produce grand generalisations, but to thoroughly understand the phenomena under investigation. Yin (1994) adds to this by explaining that the case study does not represent a sample '*and the investigator's goal is to expand and generalise theories (analytic generalisation) and not to enumerate frequencies (statistical generalisation)*' (p.151). convenience sampling

The numbers of case studies examined in this study are purposefully small and *instrumental* to providing insight into the consultation between a Pakistani patient and their health professional. Unlike the *intrinsic* (Stake, 1995) case study it is not undertaken because the case itself is of interest, for its uniqueness and peculiarity which has drawn the researcher's attention to it. Case studies are explored as part of a *collection* of case studies which have something in common and play a supportive role in facilitating our understanding of something else; in this case, diabetes consultations between Pakistani patients and their health professionals.

#### **4.17 Data Analysis**

Data analysis is arguably the most complex and challenging phase of a qualitative study. Thorne (2000) explains that findings need to be generated by transforming raw data into new knowledge which requires the researcher to actively engage in the demanding analytic processes throughout all phases of the research. Understanding and making explicit these processes is therefore an important aspect of doing qualitative research (Thorne, 2000). Increasingly it is recognised that the language of analysis can be confusing and it is sometimes difficult to know what the researchers actually did during this phase and to understand how their findings evolved out of the data that were collected or constructed (Thorne, 2000). Making explicit the analytical strategy is important because not only does it showcase the rigour and quality of the data analysis procedures but it also gives readers an insight into the minutiae of doing data analysis which may help inform future research protocols. Therefore in this section of the chapter I will describe and explain the processes and steps involved in my analysis of the case studies collected for this study.

The theoretical lens through which the data for this study were analysed is governed by the epistemological position of social constructionism and symbolic interactionism as described at the beginning of this chapter. The set of assumptions, principles, and even values about truth and reality, is underpinned by the recognition that the relevant reality as far as human experience is concerned is that which takes place in subjective experience, in the social context, and in historical time. Thus, my concern was with uncovering knowledge about how people thought and felt about the consultations in which they found themselves. Also, I analysed how people's 'social realities' compared with my observations of the consultation interaction and how different people in the same consultation could construct the same or a different reality and why. Indeed as discussed earlier, the data I choose to present to the

reader has been subject to my interpretation and is likely to have been influenced by my subjective experiences during the data collection process.

In qualitative research data collection and analysis processes tend to be concurrent, with new analytic steps informing the process of additional data collection and new data informing the analytic processes. Hence, it is important to recognise that qualitative data analysis processes are not entirely distinguishable from the actual data (Thorne, 1990). The theoretical lens from which the researcher approaches the phenomenon, the strategies that the researcher uses to collect or construct data, and the understandings that the researcher has about what might count as relevant or important data in answering the research question are all analytic processes that influence the data (Strauss and Corbin, 1998). Furthermore, as I found in this study my presence in the consultation, actions and respondents reactions to me was data in itself which needed to be reflected upon in the analysis. In line with grounded theory (Glaser and Strauss (1999), the theoretical interpretations arising from this study were grounded in the empirical reality reflected by my findings. In the next section I will describe the different stages involved in the analysis of this data and the strategies used to make sense of the data to form a coherent understanding of the cross-cultural consultation.

#### **4.17.1 Analysis during data collection**

Data were analysed in two stages; during data collection when parts of the data were analysed; and, after data collection when the whole data-set was analysed using the constant comparative approach.

I began analysing the data soon after I started the fieldwork for this thesis. There were two reasons for this. Firstly, since each case study had several inter-related components to it, I needed to ensure that the data I gathered for each component could be related back to all the different components. I analysed each patient interview before the consultation to remind myself of the issues that were discussed, for instance; what issues patients intended to raise in their consultations, and information about their management regimen to see if this matched what they told their provider(s). Once I had observed the consultation, and in order to prepare my post-consultation interview schedules for each respondent, I analysed the observational data before these interviews. This was time-consuming and required a lot of thought especially if the case studies were large and contained several post-consultation interviews. Each post-consultation interview had to be tailored to reflect what happened in

the consultation and the person (i.e. health professional, patient or interpreter) I was interviewing.

I undertook my analysis concurrently with data collection because it formed an important step in my sampling strategy. This was particularly relevant when I was in the midst of an intense period of data collection and had more patients opting into my study than I actually needed in order to complete the data-set. I had to make decisions about which patients to recruit out of the ones who met the inclusion criteria. Firstly, decisions to include or exclude patients was based on convenience sampling. For example if there were two patients who both had their consultations on the same day then for logistical reasons I could only include one of them in the study. My choice was informed by reflecting on the kinds of patients already included in my study, for example at one point I had more males in my sample than females thus I made an effort to balance the difference by choosing to include more females. Out of the 13 patients who met the inclusion criteria I included 10 in my sample.

Undertaking analysis concurrently with data collection was not always easy. Ideally, I would have preferred to have a transcript of each observation and interview before compiling the relevant interview schedules. However, this was often not possible as transcribing at the same time as collecting and analysing data was simply not feasible. On occasion I did have the help of a professional transcriber who sometimes produced transcripts in time for my next visit into the field. When I did not have a completed transcript I would listen to the audio-recording of the interview or observation or both and make extensive notes, from which I would compile the relevant interview schedules.

Thus, during data collection I had already compiled a catalogue of emerging findings which were recorded in the form of notes and then transferred into a table to help me identify some of themes that were cross-cutting across some or all the case studies that I gathered so far.

#### **4.17.2 Analysis after data collection**

Analysis of the case studies was undertaken in two stages and involved within-case analysis and cross-case analysis.

#### **4.17.3 Within-Case Analysis**

Once I had finished collecting the data, I ensured that most of the interviews and observations were transcribed so I could begin to analyse the complete dataset. I arranged all the case studies in separate folders and gave them all numbers. Firstly, each individual case study was thematically analysed to explore any discrepant (and matching) views between respondents' interview accounts and my observations of the consultation. For instance, patients' expectations (explored through their pre-consultation interviews) were compared with what I observed in the consultation and subsequently these data were compared and/or contrasted to patients' post-consultation accounts. Similarly, healthcare professionals' and interpreters' accounts of what they thought happened in the consultation were compared with what I observed. Finally, the interview accounts of all respondents belonging to a particular case study were compared and contrasted to identify agreements/disagreements between them. The overall idea with this type of 'within-case analysis' (Stake, 1995) was to become intimately familiar with each case study and to treat each case study as an individual dataset. It enabled the data to be analysed systematically and allowed the main themes arising from each case study to be recognised before comparisons were made between all the case studies.

#### **4.17.4 Cross-Case Analysis**

The second stage involved comparing and contrasting individual case studies with each other to identify themes that were common across some or all the case-studies but also to explore the diversity and differences between the case studies. For this stage of the analysis I used the constant comparative method of analysis (Strauss and Corbin, 1998). Constant comparative analysis evolved out of the sociological theory of symbolic interactionism (Charmaz and Lofland, 2003). This strategy involves taking one piece of data (one interview or observation transcript) and comparing it with all the others that may be similar or different in order to develop conceptualisations of the possible relations between various pieces of data. In addition to this, I synthesised the main findings for each case study in tables. One table represented one case study. This not only helped me to cope with the large volume of data that had been generated but also each table could be placed alongside other tables, which proved useful when it came to comparing and contrasting the case studies for cross-cutting themes.

In the following four findings chapters, I chose to illustrate six out of the 10 case studies that I gathered for this study. Three of these include the case studies involving interpreters and 3 out of seven case studies not involving an interpreter were chosen. My choice was informed by a decision to illustrate a diverse range of case studies that not only highlighted findings that were unique to individual case studies but also illustrated findings which cut across most of the case studies belonging to this dataset. The four case studies that are not detailed to the same extent as the other six, provide equally good examples of some of the main findings emerging from this study but I deliberately chose examples which included patients with varying English speaking abilities. This was to show-case how language skills and the lack of this, may influence and impact upon the consultation interaction.

In the following four chapters I will present data from six case studies involving Mr Khan, Mr Ibrar, Mrs Nargis, Mr Shabir, Mr Raza and Mrs Salma. These chapters will be followed by a summary of the key findings in which I will briefly draw upon the other four case studies to reinforce and support some of the key issues and themes arising from my analysis.

In the following chapter, I present data from one case study. In presenting a complete case study in detail I hope to give readers an insight into how ‘within-case’ analysis was a powerful way of understanding the consultation interaction from multiple angles. It illustrates how the analysis of the interview and observational data complemented each other to give a deeper and richer understanding of the consultation processes than would have been possible had only one data source been used.

Patients’ names used in the following chapters are all pseudonyms.





## **CHAPTER FIVE: CASE STUDY MR KHAN**

### **5.1 Introduction**

In this chapter, I present data from one case study involving a man called Mr Khan. The reasons why I have chosen to do this are two-fold. Firstly, this case study offers a starting point for introducing some of the themes and issues which I am then able to further develop in subsequent findings chapters. Of all the patients that took part in this study, Mr Khan spoke the least English. Hence I will use his case study to illustrate some of the effects a language barrier had upon communication between this patient and his healthcare professional. I will also use Mr Khan's case study to highlight how barriers to effective communication, other than language, can also exist in these consultations. These non-language barriers are further illuminated in the following chapters, when I illustrate consultations between patients, who spoke better English than Mr Khan.

The second reason why I have chosen to begin with this one case study, is in order to illustrate the depth of insight that can be gained from my multi-faceted case study design. For example, it serves to illuminate how the interview and observational data complemented and enhanced each other in providing an in-depth understanding of the consultation. This case study involving Mr Khan is, on one level, one of the simplest ones to use for illustrative purposes because it has the least number of components: my pre-and post-consultation interviews with Mr Khan, the consultation and an interview with the health professional. Thus, it provides a clear example of how combining pre-and post-consultation interviews with observations is a valuable means of developing an understanding of, not only the consultation process, but also of factors outside the consultation that impacted upon the interaction.

To begin, I will describe and discuss my first interview with Mr Khan, which was conducted three days before his consultation at the diabetic clinic.

### **5.2 Pre-consultation interview with Mr Khan**

Mr Khan, an 80 year old man, lived alone in an impoverished area of Edinburgh. His wife and children lived in Pakistan. He migrated 26 years ago and worked as a chef when he first arrived. Mr Khan told me that he chose to live in this country in order that he may receive the benefits of the National Health Service, particularly as he had been suffering from

chronic illnesses. He had been diagnosed with diabetes for over 20 years and also suffered from heart complications. To carry out his pre-consultation interview, I visited Mr Khan at his home. My first impression was that he appeared to be an agile man given his age, but had seemed somewhat isolated and was living in strange conditions. The curtains of his dimly lit lounge were drawn and the furniture was strewn with sheets and clothes. Food items and cooking utensils, such as pots and pans, were randomly dispersed throughout the room. His surroundings generally appeared to have been sub-standard for anybody to be living in, and my initial impressions were driven by sympathy as there was a sense of desperation and destitution about him.

Mr Khan appeared to have been wearing the only set of clothes he owned as they were stained and ripped in places and he wore a tattered hat. He appeared uncomfortable and guarded in my presence. For example, he seemed uncertain of where to sit relative to the seat he offered to me, indicating that he was not used to visitors or a female one at least. He appeared averse to making eye contact with me. I sat down but Mr Khan remained standing and I urged him to take a seat. However, instead of sitting on the sofa opposite me, he chose to sit on a pile of boxes a few feet away from me. His reaction to me made me feel uncomfortable and unwelcome but I was also gripped by a sense of sadness as I assumed he lived a very isolated and not very happy life. I also felt doubtful that I would be able to engage with him for the purposes of the interview as he had seemed uncommunicative and remote.

Nevertheless I began the interview in Punjabi and, to my relief, Mr Khan seemed to welcome the opportunity to talk. As my interview with Mr Khan progressed, it struck me that, despite appearances, this man actually had a precise routine to his days, and with what seemed little support, in terms of family and/or friends, he appeared to be rather successful in managing his illnesses. On closer inspection of the room, there seemed an unusual order within what had initially seemed to be disorganised and chaotic surroundings. For instance, all his appointment cards and medication, as well as my invitation letter, were meticulously laid out on a small table which seemed to enable him to recognise what each item was. He was able to show me which of his letters corresponded to which clinics and, he had memorised the dates of his upcoming appointments.

Mr Khan had told me he had received no formal education and was completely illiterate, in other words he was unable to read or write in English or Urdu. Despite this, he said he was

managing to take his numerous medications correctly, arrange prescriptions for repeat medication and attend most of his appointments. He had also successfully opted into this study by drawing on help from the local Pakistani community. When I asked him how he identified his different medication he explained that:

*“I am illiterate but am taking an interest in learning how to identify numbers etc and other little things but I cannot write. I can recognise my medication by the numbers they have written on them (medication boxes) and sometimes I can join up big English letters and get by.”*

Mr Khan described how, despite living alone and not being able to communicate in English, he was able to live independently:

NA: *“Do you ever find life hard here because in your home country everyone speaks your language and here you have to speak English wherever you go?”*

Mr Khan: *“No it’s not that bad here it’s not hard. There are organisations like Milan (a local South Asian community group) and they can fill out your forms for you and also on [place name omitted], the Pakistani society, they will fill out forms for me. They will write out the Urdu for me. They will help talk for you and or fill out forms.”*

The above excerpt illustrates how Mr Khan had actively created the support system necessary to deal with written materials and to enable communication between him and statutory agencies, such as social security and housing departments through bilingual advocates. Mr Khan’s previous occupation as a chef enabled him to cook for himself and he boasted to having a good diet which compromised limited sweet items and very little salt. He also described walking regularly to the local Pakistani-run shops for some casual company as well as his food supplies.

Once I felt I had established some kind of rapport with Mr Khan, I began to ask him questions about his past experiences of consultations. He responded by talking about how:

*“The doctors are good, they give me medicine and they keep an eye on me. They do everything really well. You can’t praise them enough.”* [Long pause whilst looking at medication]

Mr Khan offered praise and positive feedback about the health professionals and the services they offered on several occasions during the interview. Given that, by his own account, he

spoke limited English, I was curious to explore how he managed his consultations, and how this influenced his positive perceptions.

NA: *“When you go to see your doctor, how do you manage to explain yourself to the doctor?”*

Mr Khan: *“Yes I can they understand and its perfectly fine how things are going. When there is a need to discuss something then they arrange for an interpreter but when I need my medicines etc, I just go by myself. I can tell minor ailments myself.”*

It appeared that Mr Khan did not consider the ability to speak English as a necessary precursor to enable him to navigate his consultations, and why he felt this way can partly be understood in terms of the expectations he held from his consultations:

NA: *“What usually happens in these [diabetes] consultations?”*

Mr Khan: *“The nurse firstly takes the blood and sends me back to the hall and then after the doctor sees me and then he asks me and he checks my blood pressure. And then he tells me himself, that your blood is fine and your urine is fine and to make another appointment.”*

Mr Khan’s expectations of his consultations appeared to have been quite limited and mainly centre upon him receiving medication (illustrated in the previous quote) and blood tests. For such limited expectations to be fulfilled, being able to speak the same language as the health professionals was perhaps not necessary. To further explore how he had been communicating in these consultations, I asked Mr Khan how he talked with his health professionals and replied:

*“When the doctor calls you in he tells you himself, he interviews you and tells you ‘your blood ok, urine ok’ (words spoken in English) and like that he tells me everything, then he checks the blood pressure and he tells me it is absolutely ‘fine’ (word spoken in English) and, if it is a bit high, they will tell me. I have to take my medication as they check them too to see what ones I am taking.”*

In the above excerpt the words spoken in English by Mr Khan sounded as if they were well rehearsed which gave the impression that he had learned to listen for, and recognise, what he perceived to be the key words that were often spoken during his consultations, such as “fine”, “blood”, “urine” and “ok”. I found it difficult to believe that he would be attending his forthcoming diabetes consultations unable to speak English, bar a few words and without

interpreting support. However, Mr Khan said he was going alone and had been doing so for the past 20 years:

NA: *“On Thursday will you go by yourself?”*

Mr Khan: *“Yes I will go by myself. I will take my urine sample and they will take my blood test...they always tell me ‘your result ok.’”*

As indicated earlier Mr Khan had been very pre-occupied with a current health problem, namely heart palpitations. His concern with this matter often made it difficult to focus on exploring issues to do with his diabetes consultations during this initial interview. On several occasions when I asked him specific questions about his upcoming consultation, such as what issues he might raise, he used these opportunities to explain his concerns about his heart and how he had wanted me to help him to obtain a solution for this problem:

*“I would like you to help me with this problem that I get at night. I was so pleased to get your letter. I was so pleased that someone from our country would come and meet me.”*

Mr Khan told me he had been experiencing loud thudding noises in his ears every evening and that he believed these noises were arising from his heart. I explained that I would not intervene during the consultation and that he would have to explain this problem himself. I felt Mr Khan expected help from me and I found it very difficult to deny him any hope of this. Hence, I offered to talk with the doctor on his behalf once the consultation was over if he felt it was necessary. It appeared he had understood and I followed on by asking:

NA: *“How will you explain your heart problem to the doctor?”*

Mr Khan: *“I will say that ‘my chest high’ (words spoken in English), that’s how I will explain it to the doctor. So when I say my chest is high then he will say fine and he will write something out.”*

Returning to the question about the kinds of expectations Mr Khan had held of his consultations, it appears these centred upon receiving test results, as illustrated above, and on wanting medication as seen here. Even though Mr Khan’s expectations appeared to have been limited, his ‘needs’, it seemed, were far more complex. He repeatedly pleaded for my help but, at the same time, seemed fairly confident that he would be able to describe his problem to the doctor despite his limited English. I felt that this was, in part, because I had offered to help him and he was therefore optimistic about a solution. I also felt that he had

also wanted to give me the impression that he was competent and was able to successfully manage his consultation by himself. Within the perimeters of his consultation expectations, he had viewed his past interactions with the doctors to be relatively straightforward. As the above excerpt illustrates, he had perceived that the doctor would understand him, reach a diagnosis and prescribe medication simply by following his very limited explanation of his symptoms. However, if things were going to be as straightforward as Mr Khan had claimed to anticipate, it raised the question for me of why he was insistent that I helped communicate his problem to the doctor? I asked him whether he had raised this concern before and he told me he had done so at the cardiovascular clinic he attended:

*“I’ve told him that ‘my chest uh the have eh busy’ (words spoken in English), there is a lot of ‘bum bum’ noise in my chest. They have given me a spray and told me to spray.”*

However, Mr Khan had said the spray only helped during the day and, he had wanted me to obtain a better drug for him which would permanently address this problem. It therefore seemed that Mr Khan had been unable to obtain a satisfactory outcome using his limited English and sought another avenue to try and obtain the result he wanted. So prominent was this feature in his account, I found Mr Khan’s insistence, on discussing his heart problem, often curtailed exploration of other issues in his pre-consultation interview.

I have so far described how Mr Khan, who lived alone in deprived conditions, suffered from debilitating health problems, spoke very little English and attended his consultations by himself. Despite this bleak picture of his circumstances he had actually come across as an optimistic person who conveyed gratitude for, and satisfaction with, the services he had received. His consultation expectations had appeared limited which centred upon undergoing tests and receiving test results and the receipt and review of his medication. It seemed Mr Khan had perceived me as someone who could possibly help him to obtain effective medication for his heart palpitations which raises two questions: his motive for taking part in my study; and, whether, given his limited understanding of English, these consultations had really been addressing his needs. I will now describe the consultation interaction between Mr Khan and his health professional.

### **5.3 The consultation**

When, Mr Khan arrived at the hospital at which his diabetes review consultations usually took place, he did not know which health professional he would be seeing. My second

meeting with Mr Khan was in the waiting room prior to his consultation. I arrived at the hospital after Mr Khan and sat myself with a chair between us so that he did not feel uncomfortable. His clothes had appeared much cleaner than at our previous meeting. He pulled out a piece of paper from his pocket on which he told me he had asked one of his friends to write (in English) a brief description of his heart problem so that the doctor could read it. I looked at the piece of paper and saw that the writing was illegible. Shortly after, Mr Khan was called into the consulting room by a male doctor who was wearing a suit and who had a strong Irish accent. The doctor, a diabetes consultant, appeared to be in his fifties and, from my post-consultation interview with him (described later), I discovered that he had an interest in research related to ethnic minority patients and diabetes.

The consulting room consisted of a desk with a computer, behind which the doctor took his seat. Mr Khan sat at this desk, across from the doctor. I positioned myself a few feet away from the consulting pair, but sat parallel to them so both the doctor's and Mr Khan's faces were visible to me. The consultation began with the following exchange (the use of numbers is for ease of reference):

(1) Doctor: "*So how are you?*"

(2) Mr Khan: "*yes*".

(3) Doctor: "*How are you feeling?*"

(4) Mr Khan: "*Feeling ok, not bad.*"

(5) Doctor: "*any problems?*"

(6) Mr Khan: "*any problems, anything alright?*" [Tone of voice changes indicating a question]

(7) Doctor: "*You're feeling everything's ok. Good, good*"

Already we can see that the conversation between the two parties is somewhat precarious, featuring slight slippages of meanings and moments of incomprehension. Lines 5, 6 and 7 are of particular interest. In the first two lines Mr Khan gave an incorrect response to the doctor's question but because he took his 'turn' in the conversation this prompted the doctor to ask him another question. Lines 3 and 4 reflect that, this time, Mr Khan had correctly understood what the doctor said. In line 5 the doctor asks if there are any problems with Mr

Khan's health. In line 6 Mr Khan seems to have picked up on the words 'any problems', spoken by the doctor, and repeats these but also adds 'anything alright' (I presume he was meaning to say 'everything' instead of 'anything'). My understanding at the time was that Mr Khan was asking the same question the doctor was asking him in line 5. My reasons for thinking this were because Mr Khan's tone of voice became slightly raised and he looked as if he anticipated an answer from the doctor once he had asked it. I assumed that he was asking the doctor to tell him whether there were any problems with his test results. However it appeared that the doctor interpreted what Mr Khan had said as a response rather than a question, hence he moved the conversation on as can be seen in line 7. If my interpretation was correct then perhaps Mr Khan had picked up on the familiar word 'good' spoken by the doctor in line 7, in response to his question, and assumed that everything was 'good' from the doctors point of view. My interpretation was heavily influenced by my own perceptions of Mr Khan's poor English and, to me, it appeared he may have understood very little. However, the doctor may have judged Mr Khan's English differently, an issue I will explore when I describe my interview with doctor later in the chapter.

There then followed a 'discussion' about the medication Mr Khan had brought with him to show to the doctor. Mr Khan brought out his medicines from the polythene bag he had in his pocket and laid them on the table between them:

Doctor: (reading the pill packets)... *"And this GTM for angina and Ferrous sulphate for Iron"*

Mr Khan: *"yes a weak tablet and the..."*

Doctor: *"mmm mmm"*

Mr Khan: *"a weak tablet"*

Doctor: *"ok who..."*

Mr Khan: *"blood"*

Doctor: *"Your blood was a bit thin was it?"*

Mr Khan: *"Yes"*

Doctor: *"Have you had any tests or investigation for that?"*



Mr Khan: (turns to me to speak in Punjabi) *“What is he saying?”*

In the above exchange the doctor begins the conversation by naming the medication and talking in biomedical terms, Mr Khan then refers to the same pills (for anaemia), by suggesting they are for his weakness (amongst South Asians, anaemia is commonly referred to as a condition which causes the body to become weakened). Mr Khan realises that the doctor is perhaps not understanding what he is referring to and instead uses the word ‘blood’ to explain why he thinks he has been prescribed these pills. The doctor appears unsure about what Mr Khan means and initiates a ‘repair’ strategy. As described in Chapter Two, ‘conversational repair’ sequences are an important aspect of communicative interaction. These sequences may occur in the event of communication failure such as if a listener requests clarification of a previous aspect of the speaker’s message. In this case when Mr Khan said “blood” the doctor sought clarification with his repair question “your blood was a bit thin was it?” which elicited a “yes” answer from Mr Khan thereby moving the verbal exchange forwards.

This example also serves to highlight how the language barrier is making it difficult to establish what should have been a fairly straightforward conversation. Not only was Mr Khan experiencing trouble in understanding the doctor but also the doctor appears uncertain as to what Mr Khan was talking about. Eventually, when Mr Khan no longer felt he could provide the doctor with an answer he turned to me for help. The first time he asked me, I asked him to keep trying to talk with doctor by himself. Again, both the doctor and Mr Khan grappled with trying to understand each other until Mr Khan turned to me a second time and asked me to explain his heart concern to the doctor. Again, I insisted that he tried explaining himself which he then tried to do:

Mr Khan: *“This...this is my chest high in the night time, sleeping time, bed sleeping, chest bum bum bum and the sound here”* [points to ears].

Doctor: *“Yes I know. Yeah a lot of people get that where they hear their heart in their ears, that’s why you call them em let me feel your pulse”* [long pause while he feels patient’s pulse]. *“Your rate is at a good level today.”*

Mr Khan: *“yes”*

Doctor: *“you do get the occasional extra beats but I don’t think they are...are a problem. I’m happy enough with your heart. When you feel it going fast is it fast beating”* [bangs his hand rapidly against the table to mimic sound] *‘or slow beating* [similarly mimics a slower sound]’.

Mr Khan: *“yes night time and the sleeping time and the little high this”*

Doctor: *“How fast does it go?”*

Mr Khan: *“Tup tup tup”* [pointing to his ear]

Doctor: *“Yes you hear it in your ears, yes, is it very bad?”*

Mr Khan: *“Morning time ok, morning time ok.”*

Although Mr Khan and the doctor keep up a fairly lengthy conversation, the discussion appears to be strewn with misunderstandings and what seems like ‘erroneous’ responses to questions. Through his questions, the doctor tries to establish the rate of the palpitations Mr Khan is experiencing; for instance, he asks *“how fast does it go”*, *“is it very bad?”* but appears unsuccessful in eliciting the response he was expecting because, quite simply, Mr Khan does not appear to understand what he had asked him. The only piece of information that appears to have been exchanged between the consulting pair (evidenced by the doctor confirming back what Mr Khan told him) is the description of the problem provided by Mr Khan. Despite Mr Khan being asked questions on three occasions, the answers he provides appear to be a response to a conversational cue rather than a response to a question he has actually understood. For instance, when the doctor asks Mr Khan *“how fast does it go?”* and Mr Khan responds *“tup tup tup.”* While it may appear to readers that he is providing an appropriate response in which he is trying to convey to the doctor the speed/timing of his heart beats, I observed that what he was actually doing was pointing to his ear to try and explain his problem using hand gestures instead, and also to emphasise his frustration with this problem. The doctor’s response *“yes you hear it in our ears, yes, is it very bad?”* suggests that he too perceived that Mr Khan did not understand what he was asking him.

However, due to Mr Khan’s timely responses he was consistently taking his turn in the conversation and so the interaction progressed. For example, Mr Khan responds with his answers at the appropriate places in the conversation, i.e. when the doctor stops talking, enabling the interaction to progress on. It is when answers are not provided by the listener speaker at the appropriate prompts that communication can break down as I will now demonstrate:

(1) Doctor: *“Alright and I don’t think you need to change the*

- (2) *pills for the blood sugars at the moment. Ok. How is*
- (3) *your diet going?"*
- (4) Mr Khan: [silence]
- (5) Doctor: "*Are you are you eh [pause] how is the diet*
- (6) *working for you?"*
- (7) Mr Khan: [silence]
- (8) Doctor: "*What are you...are you eating well at the*
- (9) *moment?"*
- (10) Mr Khan: [speaks to me in Punjabi] "*what is he saying?"*

The above excerpt is an example of a fundamental breakdown in communication. Unlike the previous excerpt, Mr Khan stopped responding and appeared as if he did not understand what the doctor was saying. The doctor tried to initiate a conversational repair strategy when he re-phrased his question and asked about Mr Khan's diet for a second time. However, his attempt failed and in desperation Mr Khan turned to me (line 10) because he was unable to take his turn in the conversation. Mr Khan hoped that I would explain what the doctor was saying and re-establish some kind of communication. I assumed that '*diet*' would be a word that Mr Khan was familiar with, like words such as '*tablets*' and '*blood*' (which according to Mr Khan, in his pre-consultation interview, were words commonly used during consultations) but perhaps the doctor's strong accent denied Mr Khan a chance to recognise the word on this occasion. The mystery of how Mr Khan had been 'getting by' in previous consultations deepened particularly as Mr Khan had previously consulted with this same doctor. Part of me thought that Mr Khan might not have been 'trying as hard' as normal because he saw me as somebody who could help him. On the other hand, perhaps he was too embarrassed about the quality of his English, given that he had told me in his pre-consultation interview that he had little trouble in navigating his consultation by himself and, to save face, simply chose to stay silent.

Communication in this consultation further deteriorated, and, on five separate occasions, Mr Khan insisted that I explain what was being said by the doctor. Initially I intervened only to

explain my position as a researcher and encouraged Mr Khan and the doctor to continue talking as they would have done had I not been there. As his requests for my help mounted up I felt under increasing pressure to intervene in order to avoid risking losing the trust and rapport that I had established with him in our pre-consultation interview. Eventually, I did help him:

Doctor: *"Has your weight changed do you think have you lost any weight?"*

Mr Khan: *"weight"*

Doctor: *"yes"*

Mr Khan: *"Um weight ok mines, no too much. The last time and this time ok same"*

Doctor: *"yes the weight is the same. Is there any chance of getting it down a little?"*

Mr Khan: [speaks to me in Punjabi] *"what is he saying?"*

NA: [In Punjabi] *"He's asking you to lose some weight?"*

Mr Khan: [speaks to me in Punjabi] *"Lose more weight?"*

NA: *"yes"*

Mr Khan: [to doctor in English] *"OK try and the"*

Doctor: *"OK see how you go with that ok ok".*

In the above excerpt, Mr Khan appears to have picked up on the word 'weight' used by the doctor which gave me the impression that he was familiar with this term. Also, his response 'weight ok' suggests that he understood this term and the general gist of the conversation. However, the stumbling block came when the doctor asked a complexly phrased question 'Is there any chance of getting it down a little?' and it was at this point that the conversation became irreparable. Mr Khan begun to get confused again and turned to ask for my help. Had the doctor included the word 'weight' in this sentence then Mr Khan may still have managed to offer a response when it was his turn to respond to the speaker.

So far I have demonstrated some of the difficulties faced by both Mr Khan and the doctor because of the language barrier between them. However, Mr Khan was not always as 'helpless' as my initial impressions of the consultation led me to believe: There was something familiar about the way Mr Khan navigated this consultation that reminded me of my earlier visit to his home. Like the strategies he had developed for his day to day living, Mr Khan seemed to have had systems and techniques which enabled him to 'get by' during the consultation. Although Mr Khan grappled with some of the things the doctor said, at other times it appeared he was controlling the conversation between them, successfully eliciting answers which he could understand.

### **5.3.1 Mr Khan's control of the consultation**

For the most part, Mr Khan appeared passive during the consultation, but there were times when he rather assertively asked the doctor questions. The questions that Mr Khan asked appeared to serve a purpose for him, in that they helped him to obtain the answers he sought from the doctor. I will now illustrate an example of this, by beginning with an excerpt in which the doctor is summarising what he perceives to be the main messages arising from the consultation:

Doctor: *"So overall I'm happy with how things are going from a diabetes point of view. I think the blood sugars are reasonable, uh on average and that's good. I think you need to continue on the same tablets that you currently take."*

I personally thought that Mr Khan would have understood very little of what the doctor had said particularly as the doctor, in my mind, used fairly complex words such as '*reasonable*', '*average*' and '*currently*'. Perhaps he did not understand these (and other) words, but surprisingly on this occasion, Mr Khan did not ask for my help and gave the following response:

(1) Mr Khan: *"Eh sugar control ok?"*

(2) Doctor: *"Yes it's ok yes so continue on the same tablets."*

(3) Mr Khan: *"Same tablets?"*

(4) Doctor: *"Yes."*

In line 1 Mr Khan appears to be asking a question and in a sense introduces a sequence in the conversation in which he sought clarification of a previous aspect of the doctor's message. One could argue that he may simply have been parroting what the doctor had said because, as I have indicated earlier, Mr Khan was quite capable of doing this on occasions. By the tone of his voice I understood that Mr Khan was on this occasion asking a question. It was a very simple and direct question which prompted a relatively simple answer from the doctor. Although Mr Khan had limited English he managed to negotiate the answer from the doctor with which he was familiar "*yes its ok*". Thus, he successfully 'repaired' the conversation. Mr Khan's anticipation of this answer can be traced back to his pre-consultation interview (second quote, page 6). What is particularly interesting is how Mr Khan strategically manipulates the doctor into giving a short and synthesised version of his longer message enabling him to receive the message that his diabetes was under control.

A similar example can be seen in line 3 when he asked the doctor a closed question "*same tablets?*" forcing the doctor to provide a 'yes' or 'no' answer. Mr Khan had successfully transformed the doctor's comparatively long statement, which could have led to 'communication failure'. into two simple and short answers: "*yes it's ok*" and "*yes*". Hence, Mr Khan came away from the consultation understanding the main messages the doctor intended to deliver.

A further example of how Mr Khan elicits responses, framed in a way that enabled him to understand them, is given below:

Doctor: "*Well, I am overall very pleased with how this is going. The average blood sugar has improved a little as we've said and so the control of the diabetes is quite good.*"

Mr Khan: "*Control ok?*"

Doctor: "*yes it is.*"

Mr Khan: "*thank you.*"

It is unsurprising that Mr Khan had picked up on the word '*control*' as this is a word frequently used in diabetes consultations. It appeared that Mr Khan listened carefully to what the doctor was saying and, even though much of what the doctor said may have been difficult for him to understand, he still managed to identify/recognise one word and repeat it back to the doctor in the form of a question. Once again the doctor was forced to supply Mr

Khan with a simple “yes” answer. Nevertheless, Mr Khan did not always seem to elicit the response he expected or hoped for.

Returning to the issue of Mr Khan’s heart complaint, it had been established during the course of the first conversation in the consultation about this matter that, Mr Khan had previously been given a cardiograph by his heart consultant. This involved his heart rate being traced for 24 hours to pick up any potential problems. However, this only came to the diabetes consultant’s attention when he was about to refer him for the same test on the basis of the limited information he obtained from Mr Khan. Mr Khan appeared to have difficulty understanding what the doctor was saying about the test until I interpreted for him. It was then that Mr Khan disclosed this piece of information and, based on this information the doctor told Mr Khan that, there would be no benefit of having this test repeated. The subject was then dropped and the doctor moved on to checking Mr Khan’s blood pressure.

Mr Khan found another opportunity to raise the issue towards the end of the consultation when the doctor asked if he had any questions. Mr Khan again turned to me to interpret what the doctor had asked:

Mr Khan: “*Uh*” [looking towards me]

NA: “*Do you want to ask any questions?*”

Mr Khan: (to me) “*no nothing, I just wanted to ask about this beat at night it gets worse then. Other than that everything is fine.*”

I interpreted this to the doctor and he ascertained through me how long ago he had been attending the cardiology clinic:

Doctor: “*Right. So quite a while, so you you...did you tell them about the palpitations in December?*”

Mr Khan: “*Yes.*”

Doctor: “*You told them about those?*”

Mr Khan: “*Long time the appointment*”

[Doctor looks towards me to presumably interpret for him]

NA: (to Mr Khan in Punjabi) *"The last time you were at the heart clinic did you tell them about your heart problems?"*

Mr Khan: (to me in Punjabi) *"yes they called me up for that the GP sent me there and they said there is nothing wrong with me."*

NA: (to doctor) "He was referred there by the GP and they said there was nothing wrong with his heart."

Doctor: *"Ok alright. Well we can't do more for that, they are the experts. Alright, ok alright. Good. I would like to see you again in another six months"*

Mr Khan: *"Ok. Thank you."*

Of note here is how Mr Khan responded at the end by saying 'Ok, thank you' in direct response to what the doctor said without requiring an interpretation from me. I sensed that Mr Khan realised that his allotted consultation time was over as he began to shuffle around in his seat. At this point, judging by his reaction and the fact that he did not obtain medication for his problem as he had originally hoped he would, I was uncertain whether he had achieved a suitable response to his heart problem. This is an issue to which I will return when I come to describe my post-consultation interview with Mr Khan.

The doctor concluded the consultation by suggesting to Mr Khan (with my help) that it would be useful to arrange an interpreter for future appointments and offered to help with the arrangements. Mr Khan quietly left the room and the doctor followed him to the reception desk to place a request for an interpreter. I waited whilst Mr Khan's follow-up appointment was being dealt with and subsequently arranged our post-consultation interview.

The doctor insisted on having a word with me after I had said goodbye to Mr Khan. As requested, I returned to the consulting room and took a seat where Mr Khan had been sitting whilst the doctor finished recording the consultation notes into his Dictaphone. Most of what he recorded was the information conveyed by me during the consultation; for example, the discussion about the cardiograph. Once he had finished, he told me that he perceived the communication between Mr Khan and him to have been a "*complete disaster*". He openly shared this sentiment with another consultant who was passing by his consulting room, telling him that he had just had a "*disastrous interview*" with a patient. I wondered if the doctor would have said the same thing had I not been there. I told him that Mr Khan had said he usually attended without an interpreter. The doctor initially appeared baffled by this,



but then recalled consulting with Mr Khan in the past and being concerned about his lack of understanding. He told me that following that meeting, he had sent Mr Khan a letter highlighting the main messages arising from that consultation (in English). Since the doctor's clinic was still running, I arranged a day when I could telephone him to further discuss the consultation I had just observed.

As Mr Khan's post-consultation interview was conducted prior to the doctor's interview, I will describe and discuss this before moving onto my interview with the doctor.

## **5.4 Mr Khan's post-consultation interview**

On this occasion, I arrived at Mr Khan's home half an hour later than agreed due to a delay in public transport. Mr Khan was wearing an apron over his shoddy clothes and carried a ladle in his hand as he led me through to the lounge. The room appeared even more cluttered than before. Once I was seated, Mr Khan disappeared through a doorway from the lounge, presumably to attend to his cooking. When he returned, he chose to sit on the arm of the sofa opposite me, guarded as before, and again he appeared to be conscious of his (or my) personal space. As before, he avoided making direct eye contact with me, which sometimes made it difficult to hear what he was saying. As I was setting up the digital recorder, he told me that he wanted to leave his home in the next 40 minutes to visit local shops and attend to some chores. He told me he went out every morning at the same time as part of his daily routine.

I immediately began the interview, which was conducted in Punjabi, and asked him how he thought the consultation went, to which his response was:

*"It was ok, it went really well"*

Given that my first interview with Mr Khan had been dominated by discussions about his concerns about his heart, I had assumed that he would have been disappointed by the outcome of the consultation as he has been unsuccessful in obtaining the prescription that he had hoped for. I asked him why he thought it and the consultation had gone well, to which he responded:

*"He (the doctor) said the blood is fine, my blood pressure is also fine and the sugar sample was also fine."*

I asked him to elaborate upon his answer and provide more details of what he meant:

*“As he said in your presence my blood is fine that it doesn’t have a lot of sugar in it and also in the urine there’s not a lot. That was discussed in front of you and they also checked me there. They checked my blood and I also had to take a urine sample. So everything was in front of you.”*

It appeared that Mr Khan’s expectations of the consultation had changed retrospectively, possibly in light of his experience of the consultation, an issue to which I will return when I describe what Mr Khan had to say about his heart concern during this interview. I also felt that Mr Khan’s constant reminders of my presence in the consultation sometimes hindered him from elaborating on certain details or events that took place in the consultation. My impression was that he was perhaps slightly bemused that I was asking him to describe his thoughts of the consultation when I had witnessed everything that had happened. It became apparent to me that this was one of the drawbacks of directly observing the consultation and, again, the following example illustrates this:

NA: *“How did you feel you communicated in this consultation?”*

Mr Khan: *“I did it the way you saw it.”*

I also found it difficult to engage Mr Khan in a ‘reflexive’ conversation about the consultation, because my motive for seeking this type of information made little sense to him. As mentioned earlier, Mr Khan’s motivation to take part in this research may have been informed by his expectation that I, being a member of his community and having the language skills, would be able to offer him some help in obtaining a resolution for his heart problem. Also, I had no way of knowing what the person said who, had presumably translated my invitation letter to Mr Khan. It raises the question of how much he understood about my role, the study and its purpose. Whereas, in the first interview he seemed keen to talk about his problems, in this interview it seemed he was simply answering my questions. Indeed, in this interview, Mr Khan refrained from raising the issue of his heart problem during this conversation. I presumed he was still experiencing the ‘worrying’ symptoms he had described previously and, would still be desperate for a resolution, but it seemed that Mr Khan had become closed off and guarded during this second visit. Despite my sometimes getting involved in the consultation as an interpreter, I actually made little difference as he was not prescribed with any pills for his heart, and Mr Khan was perhaps disappointed that my presence had not benefited him in the way that he had hoped for.

An alternative explanation could be that Mr Khan's perceptions of his problem altered and he did not feel the need to raise this issue with me anymore. Also, possibly, Mr Khan saw no reason to raise any further problems with me as he knew I would not be going to any of his future consultations with him. After giving Mr Khan the opportunity to bring up his heart related concern, I decided to ask:

NA: *"Do you still have the heart problem?"*

Mr Khan: *"Yes I do have that issue but this spray the doctor gave helps."*

NA: *"You talked about it in your appointment..."*

Mr Khan: *"I asked you to tell him that I get this beating at night a lot and you told him and then he said he would give me this meter. I have had that before but nothing came up. The GP sent me there so they checked me and sent the report to the GP so that he could write something out for me. After that the GP gave me a spray and that's helpful. It happens sometimes, right now I am fine but it happens only sometimes."*

NA: *"so it doesn't happen every day?"*

Mr Khan: *"No not everyday"*

In his previous interview, Mr Khan told me the spray did not alleviate the symptoms that he was experiencing every evening (see page 7). It now seemed the problem was much less frequent following his consultation at the diabetic clinic. His narrative had clearly changed and, other than my speculation that he no longer wished to talk to me about his heart troubles, there may have been other plausible explanations that led Mr Khan to re-construct his narrative. One possibility is that Mr Khan played down the significance of this concern in light of his consultation experience in which he was unable to resolve the problem and realised he might have to 'put up' with it. An alternative explanation could be that what initially seemed like an unpleasant experience that led him to believe that something was seriously wrong with him, seemed less serious in light of what had happened in the previous consultation.

Towards the end of the interview I asked Mr Khan:

NA: *"Did you feel you talked about everything you wanted to talk about or was there anything else?"*

Mr Khan: *“No there was nothing else, it was just the blood and sugar level. He checked my blood pressure and asked about my feet and I said ‘feet working’ (words spoken in English). He checked the blood [Mr Khan began to show me a leaflet with food drawings] Can you tell me what this is (point at a picture) here it says dhal is good does that mean the dhal shown in the picture or all dhals?”*

During Mr Khan’s pre-consultation interview, he described what he expected would happen in his consultation and the above quote illustrates that his perception of what actually happened in the consultation barely strayed from what he had come to expect. He expected to be ‘tested’ and this is what happened. Mr Khan made no mention that he, on several occasions during the consultation, struggled to understand what the doctor had said, nor did he reflect on the fact that he needed my help during it. It was almost as if these particular things never really took place in the consultation and all that mattered was that he came away with what he had understood the main messages to be:

NA: *“What are the main points that you took away from the consultation?”*

Mr Khan: *“He said the blood is fine, your blood pressure is also fine and the sugar was fine.”*

The doctor, on the other hand, perceived the consultation differently to the way Mr Khan had and, in the following section, I describe the final component of this case study.

## **5.5 Interview with the doctor**

This interview took place two days after Mr Khan’s second interview. The doctor had given me his mobile phone number, and had asked me to call him between his afternoon clinics. This interview, which was conducted in English, lasted 10 minutes.

I first asked the doctor what he had hoped to achieve during the consultation in advance of seeing Mr Khan, to which his response was:

*“Em, well, I probably wanted to communicate with him [laughs], em...I wanted to, eh...assess and look at his overall blood sugar control and, eh...check that he was up to date with his screening and his targets for his diabetes, em...and to provide any information that he needed from me to help him with that.”*

The doctor's pre-consultation expectations did not appear all that different from Mr Khan's. Like Mr Khan, he wanted to establish that his diabetes was well managed as well as providing him with *"any information that he needed"*. I then asked the doctor:

NA: *"How did you feel the consultation went?"*

Doctor: *"It was an unmitigated disaster."*

NA: *"and why do you think that was?"*

Doctor: *"because we couldn't communicate."*

NA: *"Could you understand anything Mr Khan was saying to you?"*

Doctor: *"Yes but it wasn't...I could make out the words but I wasn't sure if he knew what they meant and the other difficulty was that when I spoke to him, clearly he didn't understand what I was saying."*

The doctor's frank account gave the impression that he was genuinely concerned about the way the consultation with Mr Khan had unfolded and that, in his opinion, it should not have continued in the way that it had. From the doctor's perspective, the 'barrier' to communication had been due to a language difference. Not only was the doctor convinced that Mr Khan was unable to understand what he said but he felt the difficulty was compounded by his own accent:

*"Well how much of that's a Belfast accent versus a Leith accent, em though I think anybody would have difficulty there..."*

I recalled that the doctor had mentioned sending out a letter to Mr Khan so I asked him what he had written in this letter:

Doctor: *"I had understood he had relatives when I'd asked him before and when I'd written that letter, I had...I'm 99...I can't be 100 per cent sure...but I had said had he anybody who could read this to him if...if need be....when I sent him the letter."*

NA: *"What was the letter about?"*

Doctor: *"It was really confirming what our conversation had been about... [laughs]...two years previously because my impression was that, eh...he hadn't understood it."*

NA: *“OK. So you had sent a letter confirming what...”*

Doctor: *“which is...which is unusual for me to do em...in other words, so I appreciated that we had, had difficulty communicating previously”.*

If their previous consultation together was similar to the one I had observed then it is understandable why the doctor took further action to ensure his messages were delivered to Mr Khan. Unfortunately, when I asked Mr Khan, he could not recall receiving this letter. Nevertheless, the effort made by the doctor can be considered as nothing less than genuinely supportive and indeed an unusual action to take.

However, in sending this letter, the doctor made an assumption that turned out to be inaccurate. I told the doctor that Mr Khan lived alone to which he responded:

*‘He’s...he’s an old isolated person then, I mean, I think within his community he’s unusual’*

As Mr Khan was an elderly male Pakistani, the doctor mistakenly assumed that he had family who would have translated the letter for him. It is quite common for elderly members of a Pakistani family to be cared for by younger members and, hence the doctor’s assumption may have been justified, however this was not the case with Mr Khan. The doctor considered Mr Khan to be an atypical patient to justify his stereotypical assumptions and his action of sending the letter out to him. I asked the doctor whether he had, had experienced similar difficulties with other patients in his consultations with them, to which he replied:

Doctor: *“there are a number of patients who I see who have learning difficulties and, em...that’s in...any community”*

NA: *“in what way?”*

Doctor: *“well, where they don’t understand things”*

NA: *“right”*

Doctor: *“And this is...and...my concern is that...and, and I could be totally wrong with this...is that he’s in a very unusual position and a vulnerable position and I just wonder how he’s coping with life in general...and I just wonder how skilled he is at doing all of that”.*

Again, the doctor seems to have been making tentative assumptions about Mr Khan in an attempt to rationalise why the consultation happened the way it did. I realised that, unlike the doctor, I had had the opportunity of engaging with Mr Khan in his first language and had some insight into how he lived and saw that in actual fact he had a meticulous routine. However, the doctor could only go by his brief encounters with Mr Khan during which he had been unable to develop a rapport with him. On the face of it, communication during the consultation between Mr Khan and the doctor appeared to be difficult because they were unable to talk with each other in English. However, the doctor seemed to think that Mr Khan may have had learning difficulties which were beyond being unable to speak English:

*“I...I would equate him to one of my people who are struggling with life and may not have a great understanding of diabetes, despite even being able to speak English normally. If you see what I mean.”*

From the doctor’s perspective, it seemed, the difficulty lay with Mr Khan who did not have sufficient levels of knowledge and competence in order to fully engage in the consultation. It appeared that the doctor was not content in accounting for the ‘disastrous’ consultation as simply resulting from a language ‘barrier’. Given that Mr Khan had been attending the hospital for 20 years, the doctor may have been more concerned with justifying why something had not been done about this problem previously.

I asked the doctor:

NA: *“How do you think he managed in previous consultations? I know that you had seen him previously and other doctors have seen him too, so how do you think he’s managed in those?”*

Doctor: *“I imagine it’s been the same”*

NA: *“Yeah”*

Doctor: *“And it...it taught me also that I don’t know how translators are organised. In that situation, usually I have ...usually you can get across sufficiently to a patient that it might be useful to get a translator next time but I think he actually couldn’t even understand that well enough... [laughs]... to get a translator and hadn’t maybe the wherewithal to do that, em...so that left him very...in a very difficult situation”.*

In the above excerpt the doctor provides a self-reflexive account in which he talks about how even if Mr Khan had language and/or learning difficulties, he recognised that possibly very

little had been done to improve communication with him during past consultations. Arguably, his narrative may have been a form of self-presentation to me, as he wanted to appear as a caring and responsible health professional. The doctor's narrative could thus be understood as displaying a complex array of agendas, personal impressions, and stereotypical assumptions about Mr Khan, whilst also reflecting upon his own actions towards him. I asked the doctor why he thought I was asked by Mr Khan to interpret on several occasions and he said:

*“He was pulling you in because if you hadn't been there, he would have coped a little bit differently with...with the two of us and we would have perhaps worked harder to... I'd spend longer with him and tried to get a better understanding but clearly it was just so difficult for him that he was turning for help.”*

The doctor's point, in my mind, was valid as every time Mr Khan turned for my help during the consultation he compromised his interaction and his chances of building a rapport with the doctor. He thus viewed my presence as another factor contributing to the 'disastrous' consultation.

My impression was that the doctor had felt powerless when Mr Khan, on several occasions, did not reply to his questions but instead began speaking to me in Punjabi. Mr Khan was, unknowingly, not adhering to the tacit rules of conduct expected to take place in a conversation between two or more people. Despite his language difficulties, Mr Khan was expected to at least be seen to reciprocate and respond to the doctor's questions/comments by himself. When he did not, and I intervened, it could be argued that the interaction no longer resembled the shape and format of a 'normal' consultation.

## **5.6 Summary**

This case study has raised several important issues both inside and outside the consultation setting. Mr Khan had very poor English yet he attended his consultation alone. The consultation took place despite there being a severe language barrier and, on several occasions, communication between Mr Khan and the doctor came to a halt. On many occasions Mr Khan was unable to provide an appropriate response to the doctor's questions and asked me to help him understand what was being said, particularly when the doctor used complex language and/or terminology. At other times, Mr Khan wanted my help in conveying his problem with his heart to the doctor. However, despite these effects of a



language difference, Mr Khan was able to retrieve and understand some of the main messages arising from the consultation. It is likely that by virtue of his past consultation experiences, Mr Khan had familiarised himself with words and terms that are commonly spoken such as 'blood', 'diet' and 'control'. During the consultation he identified some of these words spoken by the doctor and used them to frame his responses to the doctor and to elicit answers that enabled him to understand what the doctor was saying. The messages/information Mr Khan took away from the consultation were those associated with his test results and medication which were the messages/information he expected to receive before his consultation.

In his pre-consultation interview, Mr Khan offered praise for the health services he received. This perception remained unchanged after his consultation despite the difficulties in communication that I had seen him experience. The doctor, on the other hand, felt that communication between him and Mr Khan had been 'disastrous' and, as well as highlighting a language barrier, drew on his stereotypical assumptions to explain why this may have been the case. Since I had gained some insight into how Mr Khan lived, by virtue of my interviews with him, I had established that the doctor's assumptions were inaccurate.

Finally, I will offer some reflections on the methods used to compile this case study. My pre-consultation interview with Mr Khan provided me with invaluable insight into his circumstances and also made me aware that he was suffering from what he saw as a distressing heart problem. I was not just a researcher to Mr Khan but a member of his community who might be able to offer him some help in resolving his concerns. Despite my verbal explanations (in addition to the written material) of my role as a researcher/observer, Mr Khan insisted that I get involved in his consultation which raised questions about what his understanding of my research was. This also had implications for the responses he gave to me both in his pre- and post-consultation interviews. Since I was not in a position to help Mr Khan and meet with his expectations that I might be able to obtain a remedy for his heart trouble, this might explain why I felt that he had become 'closed off' to me in our second interview compared with the first. Furthermore, it was difficult to explore incidents that occurred during the consultation that I had observed, because Mr Khan was aware that I had seen everything for myself.

Despite these drawbacks the benefits of combining observations with pre-and post-consultation interviews could not have been achieved had I chosen to use only one method.

For example, if I had simply observed the consultation, I might have still seen that communication was difficult between Mr Khan and the doctor due to a language barrier. However, without interviewing, then I would not have discovered that there were a multitude of other non-language barriers as well. These included the doctor's stereotypical assumptions; Mr Khan's perceived satisfaction with the health care he had received and his limited diabetes-related expectations. Furthermore, if I had chosen to only interview Mr Khan after the consultation and not before then perhaps I would not have discovered his unaddressed heart concern. Also, Mr Khan may not have asked for my help had I not established a rapport with him by interviewing him before the consultation. However, the fact that he did ask for my help perhaps highlights how difficult it was for him to raise and communicate his concerns to the doctor. Finally, had I only interviewed respondents without observing their consultation, it is likely that Mr Khan would have portrayed his consultation as being unproblematic and the doctor may have recounted a different and more positive version of the interaction to that which I observed.

In the next chapter, I will further discuss and develop some of the issues raised in the case study involving Mr Khan. Two case studies will be illustrated each involving a patient who spoke better English than Mr Khan, to further develop and explore issues which have been opened up by Mr Khan's case study; namely that there are many barriers in these cross-cultural consultations which are not just a product of a language difference.

## **CHAPTER SIX: MR IBRAR AND MRS NARGIS**

In this chapter, I will describe and discuss two case studies involving Mr Ibrar and Mrs Nargis respectively. As we have seen, many of the difficulties described in Mr Khan's consultation were due to a language barrier between him and his doctor. The case study involving Mr Khan also served to draw attention to there being other barriers behind the most obvious and visible one of language. In the following case studies, I will take forward this observation by showing how, even when patients spoke better English than Mr Khan, other barriers hindered effective communication between patients and their providers. Compared to Mr Khan, Mr Ibrar spoke marginally better English and Mrs Nargis spoke much better English still. From the previous chapter I will take forward and further develop several themes including how a language difference may not be recognised as a barrier by both patients and health professionals even though, in the case of Mr Ibrar, it clearly limited communication. I will also further develop the finding that health professionals may have personal views and stereotypical assumptions about Pakistani patients which might also help to explain why language was not always seen as a barrier by them. In this chapter I will argue that one of the reasons why Mr Ibrar and Mrs Nargis did not raise issues that were potentially relevant to their consultations may have been to do with impressions of themselves which they wished to create for the health professional and/or me. Also, I will show how, like Mr Khan, they perceived their consultations to have been 'successful' even when I observed difficulties. Finally, I will explore how health professionals' consulting styles and patients' passive demeanours may play a part in making the consultation 'problematic'.

### **6.1 Mr Ibrar**

I begin this chapter with the case study, involving Mr Ibrar because his English language skills were slightly better than Mr Khan's but not as good as Mrs Nargis', and thus this example can be considered to be in the middle of a continuum representing the language skills of these three patients. It could be envisaged that, because Mr Ibrar's English was better than Mr Khan's, communication between him and his doctor would have been more 'successful' than was seen in the previous chapter. However, this did not prove to be the case for reasons which will be described and explored below.

### 6.1.1 Pre-consultation interview

Mr Ibrar, a 51 year old man, had been resident in the UK for six years. He worked in a biscuit factory and lived in a small flat with his wife and three children. When I first interviewed him, he made me feel very welcome and generally seemed optimistic about his life circumstances. He said he was glad to have migrated to the UK and that his children were being educated here. When I arrived to do his pre-consultation interview, Mr Ibrar invited me to sit at the dining table in the corner of the small living room. The room had many things in it including a large plasma television but was tidy. There was a small kitchen which came off the living room and I could hear that someone was in it. During the interview, which was conducted in Punjabi, Mr Ibrar's wife popped in and out of the kitchen, sometimes just to listen to our conversation and sometimes to offer some comments in support of what her husband was saying to me. She wore a large shawl which covered her head and shoulders. Mr Ibrar's children were either at university or secondary school at the time of the interview.

Mr Ibrar was on insulin therapy and, although he claimed to be *"taking good care of my diabetes"*, he raised some unresolved management issues which he discussed in the context of his previous diabetes consultation at the hospital:

NA: *"ok what did they say to you in the last appointment, was anything important discussed?"*

Mr Ibrar: *"hmmmm, they just told me about the sugar because they have the result for three or four months and they said it was near eight and they said it was high so to increase my insulin, so then I increased it from 35 to 40 and after that the nurse here at the surgery...I had an appointment with her about 3 months ago and I had discussed with her that my sugar goes low as well."*

It appeared Mr Ibrar was experiencing 'hypos' which occur when blood glucose levels fall below the normal range<sup>3</sup>. Seemingly, Mr Ibrar had already discussed this issue with the nurse at his local general practice but the problem had remained unresolved:

*"Sometimes when it's really busy at work and all my breaks are over, I have 3 breaks in the company and I begin to feel it is going low. It begins*

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<sup>3</sup> 'Hypo' – is shorthand for hypoglycaemia or hypoglycaemic attacks which occur when a person has an abnormally low level of sugar in their blood. This is dangerous because the brain is dependent on a constant supply of sugar for energy. Some of the reasons why this may occur is because patients have either taken too much medication and/or missed a meal.

*to get low about three or four o'clock and before that it never goes low because I have just eaten earlier on. But later on when all my breaks have run out it's then I feel that way so I take juice with me inside or I will say to one of my colleagues that I am having a bit of a problem and that I need to go and so they let me go into the canteen."*

He also made reference to the problems he was experiencing in a later part of the interview when he said:

*"...when my sugar is low then I cannot drive the car. I can travel in the bus but what will I do at work when I am feeling not right, I may have some kind of accident."*

Mr Ibrar also told me how he used to drive forklift trucks at work but, since starting on insulin, he was no longer permitted to do this by his employer. He also told me that he had taken a lot of time off work, firstly before starting on insulin therapy when his diabetes control was problematic and causing symptoms but also after starting insulin due to the hypos he was experiencing<sup>4</sup>. He said he was at risk of being made redundant because his employer had stopped being understanding about, and supportive of, his health problem. Mr Ibrar was worried that a hypoglycaemic attack might occur in a situation which could result in him being involved in an accident. Since he appeared very worried about these attacks I asked him:

NA: *"Will you tell the doctor about your hypos?"*

Mr Ibrar: *"I have told the nurse and I have told the GP. I want to talk about my hands and how they are giving me a problem, my feet too..."*

I had assumed that Mr Ibrar would want to raise the issue of his hypoglycaemic attacks in his upcoming diabetes consultation. However, it appeared as though Mr Ibrar had bracketed off this issue as something which someone else (the nurse or GP) was there to deal with.

I asked Mr Ibrar why he thought he was suffering from these attacks and he explained that, in order to bring his average glucose readings down which were high in his last diabetes consultation, the doctor advised him to increase his insulin doses. He was also advised to do more exercise and at this point in the interview his wife interjected:

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<sup>4</sup> The symptoms of hypos can include: headache; mental confusion; loss of memory; double vision; temporary paralysis and seizures; trembling, faintness, palpitations and excessive sweating.

Wife: *"He doesn't do any exercise, when he used to walk the pain in his foot would increase."*

Elaborating on his wife's comment, Mr Ibrar explained that he was having difficulty doing any exercise:

Mr Ibrar: *"I have tried to go swimming, I went one time and on the very first day I had a bit of a problem when I went home. As I told you before, when you bathe your sugars drop and also at the pool I took some steam (sauna). When I came home I cycled on my exercise bike for a while, I don't normally have much time to use the bike but if I exercise too much I have a problem... [interrupted by his wife]."*

Wife: *"They (he) just came out of the gym and became over-heated and then suddenly came out in the cold wind."*

Mr Ibrar: *"even though my son had come to pick me up I still suffered and then a sharp pain in the foot is triggered off by walking."*

Mr Ibrar told me that he used to go for walks with his wife as a means of exercising but since the pain in his foot had begun he had discontinued this. In the above excerpt, Mr Ibrar and his wife present a complex medley of reasons to explain why he was unable to exercise, which can be understood both in terms of their personal experiences and their 'cultural beliefs'. In an earlier part of the interview, Mr Ibrar had described how he was convinced that his blood sugars dipped after a warm shower and how he had tested (using a monitor) his blood sugars several times before and after his showers to corroborate his belief with numerical evidence.

*"I have checked it myself, I check it before going in (to shower) and then after I come out and it definitely goes low."*

Swimming and sitting in a sauna, according to Mr Ibrar, had a similar effect, which left him feeling unwell when he arrived home. His wife explained why this happened by drawing upon a common cultural understanding amongst Pakistanis; namely, that if a person is exposed from one extreme temperature to another it may be detrimental to their health. By presenting matters in this way, both Mr Ibrar and his wife accounted for why he was unable to exercise, inferring that his motivation to do so was curbed by health and contextual problems, like the weather, over which he had little control. Mr Ibrar intended discussing the pain in his feet with the doctor but it was unclear how much of what he had told me, he actually intended on telling the doctor:

NA: *“ok in your consultation what issues do you want to talk about?”*

Mr Ibrar: *“well the pain in my feet, I used to have pain in my back and then it moved towards my feet and it has kind of got stuck in my heel and sometimes I feel the pain radiate towards other parts of my feet, maybe it’s got something to do with my blood circulation. I am worried.”*

It appeared that Mr Ibrar wished to raise the issue about his feet but it was less clear whether he would talk about his hypoglycaemic attacks. I wondered if he would talk to the doctor about the difficulties he had encountered during swimming, bathing and walking seeing as it was affecting his ability to do exercise and hence his ability to control his blood glucose.

Mr Ibrar’s consultation took place at the hospital the day after my interview with him. He usually attended his consultations without an interpreter and when asked if he would prefer to have one his response was:

*“According to me I don’t think so I don’t like to be dependent on anyone, I just get on with it myself because this is a life-long thing so what is the point in having someone come with you every time.”*

Instead of relying upon interpreters, he told me he was attending English language classes so that he could improve his spoken English.

## **6.2 The consultation**

Mr Ibrar was joined by his wife on the day of the consultation but she remained in the waiting area when the doctor called him into the consulting room. A medical student was seated in the corner of the small room which made it quite difficult to create a suitable distance between the interacting pair and myself, so I did not feel very discreet. Mr Ibrar sat next to the desk at which the doctor was seated and, the doctor moved to the edge of the desk bringing himself closer, to and almost directly facing, Mr Ibrar. The doctor was male and the youngest health professional who took part in the study. The consultation began as follows:

Doctor: *“How have you been finding the insulin?”*

Mr Ibrar: *“Eh...40...four zero...morning and evening, two times”*

Doctor: *“Ok. You’re taking 40 now morning and evening?”*

Mr Ibrar: “Yes”

The first question the doctor asked could have prompted Mr Ibrar to share some of his concerns about the hypoglycaemic attacks he had been experiencing but, instead, he responded by giving the doctor the numbers of his insulin dosages. As happened in Mr Khan’s consultation, it initially appeared that a language barrier stood in the way of effective communication as the conversation between the doctor and Mr Ibrar continued in a rather precarious way.

The doctor asked:

*“And how are you finding it? How are you finding the control? How are you finding things?”*

In posing this question, the doctor again attempted to open the door to Mr Ibrar sharing his concerns, however Mr Ibrar’s response indicates that he may not have understood what the doctor had asked him:

*“Eh...for dieting...diet and, eh...some exercise.”*

Indeed, this response suggests that Mr Ibrar had guessed what the doctor had asked and had offered a response accordingly. Nevertheless, the doctor took the lead from what Mr Ibrar had just said and continued the conversation:

Doctor: *“Ok...(pause)...how often are you exercising?”*

Mr Ibrar: *“cycling in home...and eh...goes for swimming pool for swimming and nearly half an hour work everyday”*

Doctor: *“Well done. That’s very good [pause] a model patient.”*

Mr Ibrar, as can be seen, told the doctor that he was exercising regularly by cycling at home and going swimming for half an hour every day, contradicting the account he had previously presented to me. By saying this, he elicited praise from the doctor. Even though this could have been an opportunity for Mr Ibrar to raise his concerns about not being able to do exercise because of his sore foot and his hypos, he ‘chose’ not to disclose this information. Mr Ibrar’s contradictory accounts could be explained in terms of the impression he wanted to create of himself to both me and the doctor, which is something I will explore later in the



chapter. The conversation continued with much discussion around the results of Mr Ibrar's blood glucose monitoring, during which Mr Ibrar told the doctor that his blood glucose levels were in the normal range when he checked them at home. The discussion continued with the doctor referring to Mr Ibrar's average blood glucose reading:

Doctor: *"OK. Em...what I'm a little worried about is your average is 8.6. That's your average reading."*

Mr Ibrar: *"yes."*

Doctor: *"And that's...that's a bit too high."*

Mr Ibrar: *"Mmm."*

Doctor: *"So we need to improve that if we can."*

Mr Ibrar: *"Yes. Bring down."*

Doctor: *"You are doing all the right things by exercising, which is good and trying to do a sensible diet and you're measuring your blood sugars. I was wondering if we could increase your insulin cautiously."*

Mr Ibrar was told that he was doing *"the right things"* on the assumption that the information he gave about his management regimen was accurate. Moreover, he was told that he was 'trying to do a sensible diet', yet at no point during the consultation was Mr Ibrar asked what he was actually eating or how regularly and in what amounts.

It is worth noting at this point that, in some ways, this doctor's consulting style was markedly different from the other doctors who took part in the study. Not only was his 'seating position' friendlier, this doctor was also inclined to ask more open questions in which, he gave Mr Ibrar the opportunity to lead the conversation. Examples of the doctor's open-ended questions can be found on the previous page 131 when he asked Mr Ibrar "how are you finding things?" and also on page 130 when he asked Mr Ibrar "how have you been finding the insulin?". Some of the other health professionals sometimes did ask open-ended questions at the beginning of the consultation to get the conversation started and then would switch to asking direct and closed-ended questions. However, Mr Ibrar's doctor appeared to have a mix of open-ended and closed-ended questions throughout the consultation. Another example of the doctor's open-ended question is illustrated on the following page when the

doctor asked Mr Ibrar “how does the pain bother you?” Also, unlike the other doctors, he also offered continuous praise to Mr Ibrar despite his average reading being too high.

Mr Ibrar’s average reading was high and because little or no association could be established with either his exercise regimen and/or diet during this consultation, an increase in his insulin dose was instead suggested to help lower his blood glucose. As mentioned earlier, Mr Ibrar had told me that he had also been advised to increase his insulin at his last appointment. The doctor explained to Mr Ibrar that, ideally, his morning readings should be between 5 and 9 and went on to say:

*“That’s for really good control. I don’t want you going lower than that cos you’ll feel symptomatic and you’ll have disturbed sleep but higher than that, I’m worried about the complications of diabetes and I’ll just bore you again with those...the risk of stroke, heart disease, it’s a common cause of blindness and it can also affect the nerves in your feet causing problems there.”*

Here, the doctor offers a long and complex statement which suggests that he had assumed Mr Ibrar was better able to understand him than was actually the case. Nevertheless, just as soon as the doctor mentioned the word ‘feet’, Mr Ibrar instantly responded and chose this moment to mention the problems he was experiencing:

*“Yes. Actually the start problem is feet.”*

There followed a discussion about Mr Ibrar’s current problem with his feet, what treatment he had had in the past, and which was accompanied by a detailed examination of both of his feet. Below is an excerpt from this part of the discussion, which again illustrates some problems in the communication between them:

Mr Ibrar: *“Pain start this place”* [touches sole of his foot].

Doctor: *“Ok... [Pause whilst he looks at the foot]...alright [pause]...and what sort of pain is it?[Pause] What sort of pain?”*

Mr Ibrar: *“Yes.”*

Doctor: *“Is it a dull pain, a burning pain?”*

Mr Ibrar: *“Burning.”*

Doctor: *“It feels like a burning pain?”*

Mr Ibrar: *“Yes”*

Doctor: *“And when do you get the pain?”*

Mr Ibrar: nearly everyday

Doctor: How does the pain bother you?

Mr Ibrar: Pain is a lot here

In the same way as Mr Khan managed to elicit answers from the doctor with whom he was familiar, Mr Ibrar's response (above) forced the doctor to re-phrase his question. After twice asking Mr Ibrar about the pain and, when Mr Ibrar responded with a 'yes', this seemed to indicate to the doctor that he was not understanding what he had just asked prompting him to change his open ended question into a closed one, eliciting a response from Mr Ibrar that then progressed the conversation. The doctor addressed what appeared to be a language 'barrier' by giving Mr Ibrar a choice of words to choose from; namely, *“dull”* or *“burning”*. Even if Mr Ibrar was unable to articulate his complaint using his own choice of words, he could nevertheless parrot a word used by the doctor. What is important to consider here is that, in his pre-consultation interview, Mr Ibrar did not describe his pain using the Punjabi equivalent of these words but instead described the pain he experienced as *‘sharp’* and in another part of the interview he had said *“like a knife cutting through”*. On reflection, this posed the question of whether he had understood what the doctor meant, or whether he was just following the conversational etiquette by taking his turn (see chapter two) and providing an answer to a question thereby helping to preserve the 'ceremonial order' (Goffman, 1959) of the consultation.

Needless to say, the conversation between Mr Ibrar and the doctor was kept simple and straightforward in most places, and much of what Mr Ibrar had disclosed to me during his pre-consultation interview remained unsaid. Most notably, Mr Ibrar refrained from telling the doctor that the pain in his feet was preventing him from exercising. Importantly, by the end of the consultation, Mr Ibrar had still not mentioned the hypoglycaemic attacks which he was worried about experiencing at work and which could lead to him having a serious

accident<sup>5</sup>. These issues remained unaddressed/unresolved in this consultation, which is concerning as in his interview with me, Mr Ibrar seemed quite afraid of losing his job or being seriously hurt.

The doctor concluded the consultation by again praising Mr Ibrar and ending the interaction on a positive note:

*“Keep up the work...keep up the good work with the, eh...exercise. And, eh...the more weight you can get off, the easier it will be for you to control.”*

As a result of this consultation Mr Ibrar was advised to increase his afternoon insulin dose which was also worrying, given that he was already having problems with hypos.

### **6.3 Post-consultation interview with Mr Ibrar**

I interviewed Mr Ibrar a second time four days later. I asked him how he felt the consultation had gone (again this interview was conducted in Punjabi):

Mr Ibrar: *“It was better than some of the appointments I have had before, because maybe he had an ‘assistant’ [word spoken in English] with him (medical student) and you were there...due to that he was checking me properly as they know that you had come to see what was happening and the fact that you’re not going with White patients but Pakistani patients and due to that he was asking a lot more and maybe he was a bit different to other doctors.”*

NA: *“How was he different?”*

Mr Ibrar: *“He asked me a lot of questions compared to other doctors because sometimes it happens that they ask very short questions like ‘what do you want’ and they won’t give you much advice.”*

As can be seen from the above quote, Mr Ibrar appeared to be impressed with this doctor and described him as different to other ones he had consulted with. Mr Ibrar also reflected upon how he felt he had responded to the doctor’s questions:

*“Did you see when he would ask me a question I would instantly reply back to him, there may have been a few places where I didn’t quite*

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<sup>5</sup> The symptoms of hypos can include: headache; mental confusion; loss of memory; double vision; temporary paralysis and seizures; trembling, faintness, palpitations and excessive sweating.

*understand what he was saying but, according to me, I think I gave him the right answers.”*

He related this enthusiastically, emphasising how pleased he was with the way he was able to give “*instant*” and “*right answers*”. From this comment, I got the impression that Mr Ibrar may have been trying to impress me during the consultation in order to emphasise his point (made in his pre-consultation interview) that he was able to attend without an interpreter.

It also seemed that making sense of the language used during the consultation was seen by Mr Ibrar as being his responsibility:

NA: *“Were there any words he used that you didn’t understand?”*

Mr Ibrar: *“yes there are a few but I have been here a long time now so I can just about understand, there is a little difficulty though but I don’t feel it is necessary or right that I should take someone with me because I should be confident in my own self that I can go...the thing this illness is with me at all times and to take someone with me every time and then I would just be dependent on that person for them to tell me what is going on and what I should do.”*

Even though the doctor used some complex terminology during the consultation Mr Ibrar seemed to expect it as part of the consultation experience. As in his pre-consultation interview, he maintained that using an interpreter was not an option for him anymore, and asserted that it was his responsibility to manage these consultations by himself. Again, in saying this, part of what Mr Ibrar might have been trying to do was impress me by presenting himself as autonomous, and self-reliant rather than a ‘needy’ individual.

I asked Mr Ibrar why he did not raise some of his problems with the doctor:

NA: *“ok you said to the doctor you did all the exercise and I just want to understand why you said that and why you maybe didn’t explain what you were experiencing?”*

Mr Ibrar: *“I just sort of forgot but I do know that with swimming the sugar goes low, I have checked many times before bathing and afterwards... But it was I just didn’t remember to tell the doctor...And like this when I have a bath before going to work... I have the heating on and the water is always very warm too and with that the sugar will go down quite a bit and so I check before I go to bathe just in case I have locked the door from inside and*

*my sugar goes down suddenly and I might be in serious trouble and that is why I take extra care when I bathe.”*

Mr Ibrar claimed that he had forgotten to raise these issues with the doctor even though I had observed him giving a contradictory account to him. He was almost dismissive in his answer to me, moving swiftly on to explaining the problems he was experiencing as he had done previously in his pre-consultation interview. It appeared as though Mr Ibrar was trying to ‘save face’ with me as I had directly challenged him about the contradiction between what he said to the doctor and what he had previously said to me. I asked whether he had tried to go swimming again and he re-iterated what he had said in his first interview with me:

*“No I stopped going swimming because of the weather...that day I had gone for the first time and I had the problem that first day, I have a cycle at home and I have a walking machine at home and I have a rowing machine at home but I stopped doing all that because my foot was having problems and my feet would get warm and even then I wouldn’t know what had happened to my feet but when I would wake up from sleeping in the morning then I would experience problems. In the morning when I would have to go to work then there is a problem because my foot from underneath is very painful.”*

The same concerns still existed for him, but explaining such issues in Punjabi rather than English clearly came much more naturally to Mr Ibrar. As was evident in his consultation, his English was so limited that he was only able to provide simple responses to the doctor’s questions, sometimes even guessing answers. Perhaps by choosing not to raise these complex and complicated issues in the consultation, Mr Ibrar was attempting to play down the language ‘barrier’ by keeping the conversation between him and the doctor relatively straightforward and simple. Again, this may have been a face-saving strategy, as he wanted to appear ‘competent’ and ‘independent’, a feeling which may have been compounded by the fact that he did not have the aid of an interpreter and, thus may have felt more pressure to ‘impress’.

Mr Ibrar’s long standing relationship with his GP may also help to shed some light on why he was so reticent about sharing his concerns about hypos and his feet.

He told me:

*“I will make an appointment with my GP and by that time the report from the hospital will have got to him so we can then discuss that.”*

What was interesting was the way he seem to rely on his GP to discuss the outcomes of his diabetes consultation. I asked why he chose to see his GP after his diabetes consultation and his answer was:

*“I feel more satisfied with my GP, he listens to me. The appointment at the hospital happens every six months and I think that’s a long time.”*

He continued:

*“And another thing is that every time you go [to the hospital] the doctor is different and whoever’s turn it is they will just pick up their file from the top of the pile and all he will really know about me is my name [says his name] which will be at the front of the file. And he didn’t even look into the file to see which medication I was taking all he did was look at that day’s result from the blood and talked around that. They really do need to read the file first and to go through my history to see what problems I have had.”*

Mr Ibrar expressed a clear preference for seeing his GP over the hospital doctors he had seen for his diabetes consultations, partly because he could choose to consult with his GP as often as he needed whereas the hospital doctors only saw him twice a year. He felt his GP listened to him but hospital doctors were uninterested in anything about him beyond his ‘blood test result’. By presenting matters in this way, Mr Ibrar highlighted the benefits of having an established doctor-patient relationship. The GP was familiar with his medical history and had become the main port of call for Mr Ibrar. As he did not have an established relationship with the doctor at the hospital, he was less inclined to talk about issues related to his life circumstances:

NA: *“Ok I wanted to ask you know how you are having problems with your work regards your illness and absences did you feel that this appointment may have been an opportunity to bring that up?”*

Mr Ibrar: *“There would have been no benefit of talking about it to this doctor, my own GP...meaning my own doctor when I will go to see him next I will tell him that this is my problem. But this doctor I saw at the hospital he wouldn’t have done anything, the doctor here is changed every time but it’s my GP that will be of use here and he has known me for a long for about 8 or 9 years now and he is aware of all my problems.”*

NA: *“Does the GP know that you cannot walk too much?”*

Mr Ibrar: *“Yes the GP told me not to walk too much whilst they were finding out what the problem with my feet was.”*

Mr Ibrar told me that his GP (who was White and only spoke English) would write out sick notes for him and was supporting him through his difficulties at work by offering to write to his company stating that his absences were for legitimate medical reasons. Indeed, Mr Ibrar was meeting his GP in a few days to discuss not only his recent diabetes consultation but also the implications of the appeal he had lodged with his company. This suggests that he was quite successful in raising issues and getting points across to his own GP. It is worth pointing out here that this was an account that Mr Ibrar chose to present to me and, as I will go on to show in Mrs Nargis's case study, my observation of her consultation with her GP did not actually mirror her account of her experiences with her GP.

Nevertheless, given that Mr Ibrar met the doctor at the hospital for the first time and, by his own account, would probably never see him again, it is understandable that he was selective about which issues he chose to discuss in the brief consultation he had had with him.

## 6.4 The doctor's perception

This interview was conducted over the phone and lasted about 15 minutes. The doctor was interviewed after Mr Ibrar and was asked what he had thought about the consultation:

*"Well, it probably wasn't one of my better ones, em ... I don't know. It might have been, em ... I don't know ... the nature ... there were quite a few people in the room. I couldn't think to seem to get a very good open rapport going with him."*

Whereas, for Mr Ibrar, the consultation was "better" than some of his other appointments', for the doctor it was not. The doctor's and Mr Ibrar's perceptions of the consultation experience differed, which was a common finding cutting across several of the case studies included in this study. The doctor also conveyed the view that the presence of other people in the room influenced the consultation interaction but, contrary to Mr Ibrar's perception, he felt it hindered the development of a good rapport between them. He also noted that culture may also have affected rapport:

*"It may have been, em ... I would be tempted to say it was ... it's a cultural difference, em ... on the basis of ... it's not all ... it's ... yeah, sometimes you have consultations, em ... with different people and they don't seem to flow quite so well and I got the impression it was a bit stop/starty."*



It is interesting that the doctor homed in upon a cultural difference here rather than one relating more explicitly to language. As an observer, I had perceived the communication to have been partly hindered by language, yet as also described in the previous chapter, this doctor attributed the difficulties in the consultation to other factors including the way Mr Ibrar had presented himself:

Doctor: *“Usually patients tend to volunteer a bit more information. I got the impression he was too easily agreeing with everything I was saying.”*

While Mr Ibrar had been impressed at being asked more questions than usual by a doctor and had also assumed that he had been successful in giving the doctor the ‘correct answers’ during his diabetes consultation, the doctor, however, seemed sceptical as to how much he was getting back from him:

*“I ... I prefer it when there’s at least a little bit of token resistance, em ... then they give a bit more active discussion. I just prefer it when there’s a little bit more of a dynamic feedback.”*

I, too, had noted that at no point during the consultation did Mr Ibrar question, challenge or resist the doctor’s decisions or feedback. It seemed the doctor would have preferred it if Mr Ibrar had been less passive and had not appeared to have agreed with everything he had said. This way of establishing understanding is particularly salient when the patient’s first language is not English. Further examples of this will be illustrated in the following section. Interestingly, the doctor seemed to perceive that Mr Ibrar had had the language skills necessary to be pro-active in the consultation, prompting me to ask him a direct question about whether he thought language had been a ‘barrier’ between him and Mr Ibrar:

NA: *“OK. Did you feel there were any issues arising due to the patient’s competence in English?”*

Doctor: *“Not really, no. I mean, to be fair, the Type 2 is relatively easy, em ... Type 1, for example, we’ve converted someone on to a basal bolus regime I’m talking about counting carbohydrates. I think English then is more of a problem because it’s a bit more like saying ... you know, to say the phrase like ... take 2 units of insulin for 10 units of carbohydrate, 10 grams of carbohydrate is probably quite high level English ... I would have been a bit worried about going through that without ... anything more detailed with him than that but for the level he needed, I thought his English was absolutely fine.”*

NA: *"So you didn't think he needed an interpreter or ... it would have been easier or beneficial if there was one present?"*

Doctor: *"Em ... I think he'd have got away without one, em ... though had he been on a ... basal bolus regime, I would have been more concerned about that. But, em ... for his level, I thought he didn't need an interpreter."*

Like Mr Ibrar, the doctor was of the view that he was able to navigate the consultation without the assistance of an interpreter. The doctor appeared to differentiate between those consultations requiring a 'high level' of English and those which did not. This of course, begs the question of whether this consultation would have been as 'straightforward' and manageable had Mr Ibrar chosen to discuss some of his life circumstances that affected his diabetes management. Finally I asked the doctor about his general experiences of consulting with ethnic minority patients:

NA: *"Do you find consulting with ethnic minority patients different from consulting with White patients where the language is ... you know, they speak the same language as you and they maybe have the same cultural background as yourself? Do you find any difference?"*

Doctor: *"Em ... I mean ... I was born in ... born in Manchester which is fairly multi cultural so I would say ... not particularly different. I've ... I don't ... I've ... I don't like going through an interpreter."*

NA: "No?"

Doctor: *"Em ... I think that affects rapport, em ... and I always worry slightly ... have they quite ... translated it back ... because the art of medicine is to get what's in the patient's mind into your mind and the fewer barriers between that, the better and I think interpretation ... it makes it harder to build a rapport because almost ... their interpreter's building a rapport by sort of saying a nice thing to sort of welcome them in and it makes it harder to share a joke, it makes it harder to emphasise, I think through an interpreter. Cos if someone said to his interpreter, oh my mother died last week ... the interpreter's saying, oh I'm terribly sorry ... I think it kind of loses some of the meaning. So if there's an interpreter ... and even, em ... but I would much rather have an (professional) interpreter than a relative."*

Here, the doctor raised the issues about using interpreters and saw them as a barrier rather than a facilitator to communication and as hindering the rapport-building which is so important in this kind of communication.

## 6.5 Summary

In Mr Ibrar's consultation, language was clearly a barrier to effective communication as was demonstrated by the way the consultation started and by how Mr Ibrar responded to some of the doctor's questions. However, as in Mr Khan's case study, both Mr Ibrar and his doctor did not perceive it to have been a barrier and instead drew on other reasons to explain why communication had not always been easy in the consultation. Mr Ibrar explained that his long-standing and continuing relationship with his GP had discouraged him from disclosing potentially relevant information to the doctor because he had perceived no benefit in sharing this information with someone he might never see again. This resulted in the doctor making an inappropriate treatment decision regarding his insulin which might lead to serious problems in the future. The doctor found Mr Ibrar to have been passive and to have too readily agreed with everything that he had said. This, he felt, had been a barrier to establishing a rapport with him and effective communication between them.

This doctor did appear to have had an atypical consulting style compared with the other health professionals who took part in this study. Although there were moments when it seemed he was overloading Mr Ibrar with complex information, on the whole, his style could be considered to be 'patient-centred' as he showed a genuine interest in listening to what Mr Ibrar had to say through the use of open-ended questions and his body language (seating position). The doctor's consulting style could have facilitated communication between them had Mr Ibrar responded appropriately to his questions, but his language skills did not permit him to do so. However, Mr Ibrar felt that he had communicated 'well' with the doctor and that he had been able to do so without the aid of an interpreter. This could be partly understood in terms of the way he wanted to present himself as an independent and capable Pakistani man. Also, by telling the doctor what he thought he wanted to hear he managed to elicit praise and positive feedback.

I will now go on to present a case study involving Mrs Nargis. I will use this case study to further illustrate and develop some of the findings that have arisen from the case study involving Mr Ibrar, particularly in respect to providers' consulting styles, patients' passivity and patients' positive perceptions of having long-standing relationships with their GPs. I have chosen to use this case study because Mrs Nargis' English skills were much better than both Mr Ibrar's and Mr Khan's, so effectively there was no major language barrier in her consultation. However, as we have just seen and, as we shall see below, this did not mean that effective or successful communication ensued.

## 6.6 Mrs Nargis

Mrs Nargis, aged 56, had migrated to the UK in her late 20s to join her husband who was already living here. She had a science degree from Pakistan and had taught English to young children. She had invited me to observe her consultation with her GP in which she would be discussing her recent blood test results, including one for her diabetes. Since she was on insulin, her diabetes review consultations normally took place at the hospital; in her case, every eight months. Her most recent one had already taken place by the time I contacted her. Mrs Nargis spoke Urdu with me (the only one in the sample) which is the language typically spoken in the region of Pakistan from which she came. She told me that she and her husband had been planning to migrate back to Pakistan with their three children, but he had died of a heart attack a few months before they were due to leave. Her loss, coupled with her no longer being able to return to Pakistan, had left her feeling deeply unhappy. My impression, from hearing her speak English with her grandchild, was that she had a better command of English than most of the other immigrant Pakistanis who took part in the study. She lived with her son and his wife. Her daughter-in-law was cooking in the kitchen when I arrived for the interview. Mrs Nargis led me into the living room where there was a large television and a leather suite. A Pakistani channel was showing on the TV and a moderately overweight woman was showing the ingredients for a cooking recipe. Mrs Nargis told me that she spent some of her day watching Urdu channels, and from them was learning how to cook different recipes. I began the interview and Mrs Nargis, like Mr Ibrar, talked about how she associated her hospital experience with seeing different doctors:

*“In the hospital you meet different doctors; sometimes you may get the same one but not necessarily.”*

She used this to explain why she preferred seeing her White, English-speaking GP with whom she had had a continuing relationship spanning more than 7 years:

NA: *“So what is so special about Dr [name removed]?”*

Mrs Nargis: *“I feel really satisfied with him because he allows me to talk and listens patiently. On rare occasions I have to go and see another doctor but it is very rare and I don’t feel satisfied with others it is like they don’t really understand what I was saying to them.”*

Mrs Nargis said she was pleased with the way her GP treated her, and tried to ensure that most of her appointments were with him. The qualities she liked about her GP were that he

'allowed' her to discuss her problems and was patient when he listened to her. She went on to explain why he had gained her respect. She told me that she suffered from arthritis which had affected her mobility to the extent to which she was unable to walk. After trying several different treatments in the UK, she eventually got something that helped alleviate her arthritic pain from a doctor in Pakistan, whilst she was visiting relatives there. When she returned to the UK, she had asked her GP to prescribe the same medication and, according to her, he had agreed to her request, bolstering her positive perception of him.

I asked Mrs Nargis about her upcoming consultation with her GP:

NA: *"So the appointment that you have on Wednesday what do you expect from it?"*

Mrs Nargis: *"I have made this appointment because I just had a blood test taken and he will tell me the report from these tests and that's it. If I need any medication he will ask me and will write me out a prescription. Sometimes I need medication and other times I don't and that's it."*

It appeared that Mrs Nargis' consultation expectations centred on receiving test results and possibly receiving a prescription for medication. During her interview, Mrs Nargis also told me that she had had trouble keeping up her blood glucose self-monitoring, which is an important part of diabetes self-management for patients who are on insulin as it helps them to detect and treat the hypos, which are much more likely to happen when patients move onto insulin. She said that she only monitored once a week when she had been advised to do so four times a day. She explained that this was because she disliked putting needles into herself. I asked her if she would raise this issue in her upcoming consultation and she tentatively said she might.

## **6.7 Mrs Nargis' Consultation**

Mrs Nargis's consultation took place two days after her interview. In the general practice where the consultation was to be held, I noticed two other South Asian patients in the waiting area and one White patient indicating that this practice may have a high number of ethnic minority patients. Indeed it was later confirmed by the doctor that this practice had a high number of Pakistani patients. When I visited Mrs Nargis in her home she did not wear a head scarf but, on the day of her consultation, she wore one together with a long black coat. Shortly after Mrs Nargis had arrived she was called into the consulting room by the GP. The consulting room was small and narrow and had a large desk at which the doctor sat. Mrs

Nargis sat on a chair which was placed at right angles to the desk so that she sat diagonally across from the doctor. Unlike Mr Ibrar's doctor, the GP faced his desk and his computer screen for much of the time during the interaction. The doctor began the consultation by asking:

GP: *"Tell me what can I do for you here today?"*

Mrs Nargis: *"I need some medicine and I want my blood reports."*

GP: *"Alright, tell me which medication do you need?"*

Mrs Nargis: *"Some insulin and blood pressure tablets and arthritis ones, both."*

Bearing in mind that this GP appointment had been arranged by Mrs Nargis and not routinely sent out to her like her diabetes review appointments, the doctor needed to establish her reason for the visit, hence his initial question. Irrespective of the reason for this appointment, what is interesting is how the doctors' first question seemed to set the pace for the remainder of the consultation suggesting that health professionals' consulting style may be a significant factor in shaping the consultation interaction. The interaction between Mrs Nargis and her GP lasted only eight minutes, partly because the interaction consisted of very simple and short information exchanges between them.

Consistent with the beginning of the consultation the doctor continued to ask Mrs Nargis closed questions which elicited mainly 'yes' or 'no' answers. Little opportunity was created to encourage an open discussion between them. However, it seemed that the doctor was not entirely responsible for this lack of dialogue as Mrs Nargis continually supplied the doctor with monosyllabic or closed answers thereby curbing any possibility of an elaborate discussion. She did not raise any issues or ask any questions but instead just passively answered most of the doctor's questions:

GP: *"Aha [pause] ok, have you been checking your sugars?"*

Mrs Nargis: *"yes this morning I did, it was 9."*

GP: *"Right [pause while he looks through file] what's the highest you had since I saw you last?"*

Mrs Nargis: *"11"*

GP: *"11"*

Mrs Nargis: *"aye."*

GP: *"hmm mmm do you ever get any hypoglycaemic attacks?"*

Mrs Nargis: *"no"*

GP: *"do you understand what I mean?"*

Mrs Nargis: *"yes yes I understand."*

GP: *"it doesn't go too low and you feel funny..."*

Mrs Nargis: *"yes yes I know"*

GP: *"alright what's the lowest you've had?"*

Mrs Nargis: *"4.7."*

It is clear that Mrs Nargis seemed to have understood what the doctor had said, and unlike in Mr Ibrar's and Mr Khan's consultations there appears to be no 'evidence' of her parroting or guessing the answer. Here, in the midst of his questioning, the doctor tried to establish if she had understood the meaning of a hypoglycaemic attack. Instead of providing the doctor with an explanation Mrs Nargis (in a rather defensive tone of voice) simply replied *"yes yes I understand"* and *"yes yes I know"* and the doctor continued with his questioning on the assumption that she knew what a hypoglycaemic attack was. Mrs Nargis's reluctance to give answers which went beyond "yes" or "no", coupled with the doctor's persistent closed questioning, resulted in what seemed like a very limited consultation. However, this consultation was not ridden with the miscommunication and misunderstandings which occurred in Mr Ibrar's and Mr Khan's consultations and so arguably, it can be considered 'successful' in this regard, but the question is whether communication was any more effective as a consequence.

What I observed was essentially a series of brief question and answers between the pair. It appeared that, in this case, being able to speak the same language as the doctor did not facilitate a more discursive interaction. The consultation seemed 'very bare' and void of any contextual detail. There was barely any 'small talk' or rapport building gestures. Nor did having the language ability necessarily encourage Mrs Nargis to talk about issues and

concerns such as the problems she had been experiencing undertaking regular blood glucose self-monitoring. Like Mr Ibrar, Mrs Nargis did not raise this potentially relevant issue in her consultation and instead told the doctor the opposite to what she had told me:

GP: *"How often do you test your bloods?"*

Mrs Nargis: *"after 2 or er 3 days sometimes everyday."*

GP: *"at different times during the day?"*

Mrs Nargis: *"yes."*

GP: *"right, ok [long pause] are you getting in the habit of doing it now?"*

Mrs Nargis: *"aye."*

GP: [mild laughter] *"its important ok" [pause] "now" [pause while he looks through file]. "Last time you showed me some sores in your fingers."*

Mrs Nargis: *"yes but now I'm feeling this is alright, this finger I was feeling..."*

GP: *"but...no... the wee hacks in your finger the wee cuts in your fingers, you were using..."*

Mrs Nargis: *"yes, yes"*

GP: *"they've cleared up good [long pause] ok...now take off your coat and we'll get your blood pressure and weight."*

In the above exchange, the doctor was given the impression that Mrs Nargis had monitored her blood glucose fairly frequently. He told her it was important, yet did not explain why, although this may have been discussed in previous consultations. Nevertheless, like Mr Ibrar, Mrs Nargis offered contradictory accounts to me and the doctor. Instead of discussing her issues with monitoring with the doctor, and finding a resolution to this problem, she told him that she was following his advice and subsequently the doctor moved on to talking about the cuts on her fingers. Assuming that Mrs Nargis had given me an accurate account, this reluctance to disclose information may have been because she did not want to portray herself as anything other than a 'perfect' patient.



Contrary to what Mrs Nargis had told me in her pre-consultation interview, this consultation did not resemble what she had described her interaction with her GP to normally be like. Indeed, Mrs Nargis was seen to barely talk let alone discuss her issues openly.

## 6.8 Mrs Nargis' post-consultation interview

In her post-consultation interview, Mrs Nargis, like other respondents, conveyed the view that the consultation had been unproblematic:

NA: *"Did you feel he (the GP) spent sufficient time with you?"*

Mrs Nargis: *"yes I feel he did and that I was not rushed, he also asked me about every medication making sure that I had enough supplies. I think that is enough what else can he do. What else can we do I mean we cannot hold a full discussion with but just say yes or no."* [spoken in Urdu].

Mrs Nargis recognised that her limited yes/no answers had hindered the possibility of a 'full discussion', yet she speculated that this had not been a problem because there had not been much else to discuss other than assessing her medicinal needs. She suggested that she had expected a consultation to follow this simple yes/no format partly because, contrary to my impression, she had perceived her English to be limited, and thus to have hindered her ability to engage in a 'full discussion' with the doctor:

NA: *"do you want to be able to have more of a discussion with the doctor?"*

Mrs Nargis: *"I think it is fine whatever he said I understood and whatever I said he understood what more is there so discuss with the doctor, is that not right. You know what that day I didn't have anything else to say to him, all I wanted was the blood report and some more insulin."*

## 6.9 Interview with GP

The GP, in his interview, expressed uncertainty regarding how much Mrs Nargis had understood him despite having known her for over seven years.

NA: *"do you feel she understood that everything that you said to her?"*

GP: *"I'm never entirely sure about that."*

NA: *“What do you mean by that if you don’t mind me asking?”*

GP: *“Well erm she’s always very pleasant and polite and she doesn’t question anything that I say to her do you understand?”*

Clearly, this GP was sceptical about how much of what he had said had actually been understood by Mrs Nargis and, like Mr Ibrar’s doctor, he felt it had been difficult to judge because of her unquestioning attitude and simple responses. When I asked the doctor why he thought Mrs Nargis had been so passive despite her ability to speak good English he responded:

*“She may well just be very reserved coz I’m a male and you know and she’s a widow now.”*

This GP, like Mr Khan’s doctor, held what could be understood as culturally stereotypical assumptions about his patient. This GP speculated that Mrs Nargis had not been forthcoming in the consultation because she was consulting with a man and therefore, had to adopt a passive/discreet role, a situation further compounded by the fact that she had lost her husband and perhaps felt vulnerable as a consequence. Such assumptions can potentially act as barriers particularly if health professionals’ perceptions of their patients influence the way they behave towards them. The GP may have been reticent in encouraging Mrs Nargis to be an active participant as he did not want to risk offending her and, come across as being insensitive towards her cultural views. In the context of discussing ways in which the consultation could be improved, the GP further added:

*“also patients need to be aware that things cannot happen all the time as soon as they would like and we do allow that to some extent in our surgery because people who are concerned and are unwell and who need to see a doctor we try and see them as soon as we can whereas for Mrs Nargis she quite rightly waited for her appointment because she understood it was just for her results and you know even she would understand too that we’re monitoring her diabetes to make a routine appointment but the vast majority of her brothers and sisters often turn up to the urgent clinic which is not always appropriate but I don’t like to turn them away because otherwise we might not see them.”*

By referring to her fellow community members as “*brothers and sisters*” in this way, it is fair to say that the GP was stereotyping Pakistani patients as people who did not quite understand how the clinics operated and were wasting valuable resources such as the time available for urgent health matters. If Pakistani patients were turning up with non-urgent matters and creating frustration then this inevitably would have shaped the GP’s perception

of them. Instead of turning such patients away it is possible that this GP had tailored his consulting style to deal with them quickly, thereby keeping disruption to a minimum.

Like Mr Ibrar's doctor, this GP felt that his interactions with ethnic minority patients were affected by a cultural difference:

GP: *"Erm yes it is, it is different and erm again it's mostly the language problems you know and there are especially in diabetes there is sort of cultural differences."*

NA: *"what sort of cultural differences?"*

GP: *"the one thing that I'm never particularly sure about is whether they are self- medicating with things they can get abroad you know and they may not tell us."*

Here, a 'cultural difference' is described as potentially leading to the possibility that Pakistani patients may be using medicines from abroad. Crucially, the GP perceived that he was not always told the entire story when patients came to see him. It is unsurprising, therefore, that the GP perceived this to be the case given that some patients (as I have shown) did refrain from raising issues that may have been relevant to their discussions with health professionals. In a later chapter, I will describe how a patient refrained from telling her health professional that she was using herbal remedies, a situation which is reported to be quite common amongst South Asian patients (Greenhalgh, 1997; Helman, 2000). Nevertheless, the GP's perception that patients withheld information may have harboured his 'mistrust' towards Pakistani patients.

## **6.10 Summary**

In the case study involving Mrs Nargis, several issues arose most of which were also identified in the case study involving Mr Ibrar and also in the previous chapter. Like Mr Ibrar, Mrs Nargis seemed to value her long-standing relationship with her GP, which she described as enabling for her to talk openly because her GP listened patiently to her. However, the consultation interaction between this GP and Mrs Nargis did not reflect Mrs Nargis' description of her experiences with her GP. Instead, the consultation appeared limited and comprised what could be described as a 'paternalistic' interaction. For instance, the GP asked most of the questions which were direct and of a closed nature and Mrs Nargis provided monosyllabic answers and did not initiate any discussions. Like Mr

Ibrar, Mrs Nargis did not disclose potentially relevant information in her consultation, in her case to do with blood glucose self-monitoring. Mrs Nargis' success at getting her GP to prescribe the medication she wanted for her arthritis, suggests that, perhaps in the past she may not have been as passive as I had observed her to be in the consultation. Indeed she would have had to have been quite assertive to achieve this outcome. The GP, like Mr Ibrar's doctor, mentioned how it had been difficult to establish understanding because she had been so passive and polite, which suggests that he would have preferred her to have engaged more actively in the consultation. Also, like Mr Ibrar's and Mr Khan's doctor, Mrs Nargis' GP held stereotypical assumptions about Pakistani patients. The GP made assumptions about Mrs Nargis based on the fact that she was Pakistani, and that her actions must be informed by her religious beliefs. Although Mrs Nargis spoke 'good' English, her consultation interaction was still limited and narrow, as was the case in Mr Ibrar's and Mr Khan's consultations. This highlights the fact that in consultations where there is no major language barrier, other barriers may prevent effective communication.

So far I have described consultations involving direct communication between patients and their providers. In the following chapter, I will describe a case study involving an interpreter, and discuss, amongst other things, how the dynamics of the interaction alters when a third party is asked to translate. Also, I will describe and discuss how patients who were accompanied by an interpreter did not raise issues that may have been relevant to their consultations. In this chapter, irrespective of their English language skills, both Mrs Nargis and Mr Ibrar were seen to be passive during their consultations, in the following chapter, I will show how an interpreter may have discouraged the patient from raising his concerns in the consultation.

## **CHAPTER SEVEN: MR SHABIR**

In the previous two chapters I described and discussed three case studies which involved patients who did not speak English as their first language but, two of which who had poor English, attended their consultations without any interpreting support. As discussed in chapter three, interpreters are considered to be one (if not the only) way in which the language barrier can be addressed to improve communication. Consultations involving interpreters are complex because they involve a three-way interaction in which the patient and provider talk indirectly with each other. It is generally expected that interpreters will enable patients to describe their symptoms or issues in the language of their choice because they are able to address the language barrier. Interpreters are also expected to relay the patient's information accurately to the providers.

In this study, three case studies involving interpreters were undertaken. The first, which forms the focus of this chapter, involves Mr Shabir and this case study highlights some of the difficulties that can take place in triadic consultations. Mr Shabir's interpreter was professional, yet as will be shown below, this did not promote effective communication between him and his doctor. How interpreters choose to do their job varies, and in the following chapter I will describe a case study involving another professional interpreter who did appear to facilitate communication between the patient and their provider. The third case study, which will also be described in the following chapter, involved a lay interpreter and, I will show the ways in which the patient-interpreter relationship can have a bearing upon communication in the consultation. The case study involving Mr Shabir serves as a useful starting point to draw comparisons between the different interpreting styles adopted by the different interpreters including the lay interpreter.

### **7.1 Mr Shabir's story**

Mr Shabir, aged 41, migrated to the UK in his late 20s, to join his first wife and, was diagnosed with diabetes four years ago (at the time of the interview). He lived in a downtrodden and deprived area of Edinburgh, his home being one of two situated at the end of a narrow lane. Upon entering the high metal gate, there was a roofless veranda reminiscent of homes in Pakistan. I knocked on the door several times before his wife who was clad in traditional Pakistani dress came to the door. She shouted to her husband that the "interpreter was here" and led me into their living room where Mr Shabir was sitting at a

dining table. The living room was the centre of this bungalow type home with doors leading to the kitchen, bedroom and hall. Their baby and toddler were both in the room. Mr Shabir, a slim man, was also in traditional Pakistani dress. He greeted me with enthusiasm and referred to me as 'baji' (sister in Punjabi). After some small talk I began the interview in Punjabi.

In comparison to other male respondents in this study, I found Mr Shabir to be exceptionally open and emotionally expressive. He talked of his first marriage and how it fell apart because of 'family politics' involving his ex-wife's relatives. What appeared to trouble him the most was that his wife was preventing him from seeing their 10 year old daughter. He was clearly very upset about this and cried at least twice when talking about his daughter. His anguish appeared to be further compounded by the financial circumstances he had found himself in. He told me he was unable to work due to backache and that he claimed income support; however, this benefit had been stopped three weeks ago. Since he was short of money, he said he had disconnected the phone line and satellite TV and kept the heating off despite his wife complaining that the house was too cold for their children. He said he had recently borrowed two hundred pounds from a friend so that he could pay some of his bills.

Mr Shabir seemed very keen to keep talking about his personal problems, perhaps because he felt that I might be able to help him in some way; however I explained that I was interested in learning more about his diabetes and asked him why he thought he got diabetes. He said his diabetes was a product of the personal worries which had taken a toll on his health. According to Mr Shabir his blood sugars were too high and, as far as I could gather, had been for a while. Mr Shabir's wife was present in the room for most of the interview although she occasionally would go into the kitchen. She appeared quite keen to offer her comments and opinions and indeed the first two quotes are from Mr Shabir's wife, in response to when I asked Mr Shabir about his diabetes control:

*"His (diabetes) just doesn't go down, it just goes higher and higher but doesn't come down, it is not "controlled" (word spoken in English)."*

She also commented:

*"It is always high his sugar and I think if he can begin meeting with his first daughter then he would get better."*

Her perception appeared to concur with Mr Shabir's as he nodded his head while she was talking. In her view, it was not a biomedical intervention but a change in his personal circumstances that would improve her husband's diabetes control. I asked Mr Shabir what kind of treatment he was on for his diabetes and he began showing me his pills which were lying out on the dining table. Whilst showing me the tablets he was taking for his diabetes and other health concerns (which were two Metformin twice a day, Gliclazide once a day, both of which are for blood glucose control, an aspirin and a tablet for cholesterol) Mr Shabir said:

*"yes I don't know before I used to take one of these (Metformin) but it was not coming under "control" so they told me to eat two of them and it's still quite high."*

Both Mr Shabir and his wife said they were worried and frustrated by the debilitating symptoms that Mr Shabir was experiencing on an everyday basis. Mr Shabir told me that he had been suffering from diarrhoea, which is a common side-effect of Metformin tablets, since he had been taking his diabetes medicines, and, consequently, was sleeping separately from his wife as he had to make continual trips to the bathroom through the night:

*"I used to go to the GP and complain about my toilet problem at night, even now I can only lie on my bed for about 10 to 15 minutes despite taking all the medication. And the bottom of my feet burn up really badly."*

As Mr Shabir went on to explain, the diarrhoea problem was persistent and had remained unresolved:

Wife: *"he eats nothing, since he has found out about sugar he has had problems with diarrhoea."*

Mr Shabir: *"it doesn't stop."*

Wife: *"It doesn't stop he has been to the doctor about it many times as well, they give him medication but they don't understand why it's not getting controlled. As soon as he eats his meal he has to go to the toilet and that makes him very upset."*

Added to this, he told me that the soles of his feet were painful and felt as if they were 'burning up' (words he used in Punjabi), and so he had resorted to dipping his feet in cold water several times a day to gain some relief. It seemed that his health problems were in

addition to his financial concerns which were even more overwhelming. His wife told me she wanted to find employment to ease her husband's stress levels but was unable to do so as she did not hold a work permit. In trying to encourage Mr Shabir to talk more about his consultation, I asked him whether he would be raising any of the aforementioned health concerns when he saw the consultant the following day:

*"You see I would discuss it if there were any point but this diarrhoea is not a recent thing, I have had it since 2004."*

He also told me that he was once given medication to help his diarrhoea but this caused him other problems and hence he stopped taking it. I asked Mr Shabir what he expected to happen in his upcoming consultation:

*"I don't know really. They will probably check my blood and do nothing else."*

Although, Mr Shabir had described several problems which could be considered both serious and diabetes-related, he did not see his consultation as a forum in which he could raise these. Instead, and like other respondents, he expected his consultation to centre upon his blood test results:

*Mr Shabir: "The last time they checked they took blood and urine but they didn't check it. They told me they would send the result of the tests to the GP but they didn't give it to me then."*

*NA: "in the hospital you saw a doctor there?"*

*Mr Shabir: "over there a lady doctor checked me and she didn't tell me anything about the results and said the results will be sent to the doctor."*

The above excerpt demonstrates that his expectations were so limited that he did not even anticipate being told the results of his blood tests during his consultation. His past experiences of cursory encounters appeared to have shaped his expectations of his upcoming consultation:

*NA: "At tomorrow's appointment what do you want to achieve or hope for?"*

*Mr Shabir: "All I want is...you see I go all that way, I pay the bus fares and they will check me and tell me to go and continue taking the same"*



*medication which I am already taking but for me to even spend two and a half pounds on fares is very hard.”*

Instead of considering these review appointments as beneficial or even useful he felt the requirement to attend was a financial strain. In addition to his review consultations, Mr Shabir had also been asked to come to the hospital every three weeks and meet with a dietitian to discuss his dietary management and progress. However, it seemed he was not enthusiastic about discussing his dietary issues with her as he had cancelled his last appointment. He also appeared to resent her decision to not provide him with a blood glucose monitor:

*“It has been about one and a half years since I’ve been asking for one but she hasn’t given me one. I don’t want to meet her anymore. You know I can buy this machine myself as it only costs 10 pounds but I’m entitled to it for free. All she asks is what I eat, how I eat my roti, what do I eat in the morning and the evening so she asks that and writes something down and asks me to come back in three weeks and that’s all she would say and last time I didn’t go at all. There is no point of these appointments. I am so fed up.”*

Interestingly, the health professional in question could speak Urdu/Punjabi fluently and so there was no language barrier between them; however Mr Shabir view was that his consultations with her offered him little benefit.

When consulting with other (mainly White) health professionals at the hospital, Mr Shabir said he needed an interpreter but arranging one was not always straightforward:

*“I have made appointments with my GP but when I said I needed an interpreter the appointment would be delayed by a month.”*

*“The thing is when I most need to explain what my problem is I just can’t do it and a friend won’t go along with you every time.”*

His negative views about his consultation experiences appeared to be further compounded by the difficulty he experienced presenting with health problems when they arose. He told me that, on some occasions, he had resorted to self-medicating with household painkillers as the time before he could see a doctor was just too long. Hence he ended up not seeing one.

So far, Mr Shabir has presented a rather bleak picture of his personal circumstances and consultation experiences. Most of the respondents discussed so far held limited expectations

of their consultations but assumed them to be an important part of their diabetes management because they got some indication of how well they were controlling their diabetes. For Mr Shabir, however, these consultations had become something he was attending for the sake of attending and he perceived them as having little relevance, and importance for, him. Mr Shabir's consultation took place the following morning at the hospital.

## **7.2 The consultation**

### *In the waiting room*

Mr Shabir was to be accompanied by a professional interpreter who, according to him, had interpreted for him several times before. The interpreter had been arranged for Mr Shabir through the hospital. He was male, in his late fifties, and had been interpreting professionally for six years. On the day of the consultation, I arrived at the clinic before both Mr Shabir and the interpreter and waited in the waiting room. Mr Shabir arrived shortly after and chose to sit next to me. We exchanged some 'small talk' before the interpreter joined us. The interpreter and Mr Shabir exchanged brief 'niceties' after which Mr Shabir decided to swap his seat with the interpreter and sit on a chair adjacent to us, saying the interpreter and I may have "important work-related matters" to discuss. Perhaps Mr Shabir felt obliged to swap his seat as the interpreter and I had begun our conversation in English, thereby unintentionally excluding him from taking part.

After a few minutes the doctor, a female in her late forties, called Mr Shabir into the consulting room where a medical student was sitting in the corner. There was a large desk in the middle of the very narrow room and the doctor sat on a seat across from Mr Shabir and the interpreter, who sat next to each other. There were no other chairs, and the doctor left the room to get one for me. I sat immediately behind Mr Shabir and the interpreter unable to see their faces but I could see the doctor's.

The consultation began in what seemed like an 'orderly fashion' with the doctor asking how Mr Shabir was "getting on"; the interpreter then asked Mr Shabir this question in Punjabi. Mr Shabir responded by saying "fine", before the interpreter relayed this response back to the doctor. The dialogue continued in this fashion. However, before too long the sequencing of information exchanges began to alter. What was particularly notable was how the interpreter was not conveying to the doctor all of what Mr Shabir was saying. This can

be seen in the following example in which the doctor was discussing Mr Shabir's previous consultation:

Doctor: *"And we increased some of the tablets, increased the dose of some of the tablets."*

Interpreter: (in Punjabi) *"And they increased the amount of some of the tablets."*

Mr Shabir: (in Punjabi) *"yes I am eating them."*

[The interpreter looks at the doctor indicating that she could continue speaking].

Although no questions were being asked of Mr Shabir, the interpreter refrained from interpreting Mr Shabir's comment that he was taking the tablets in question. The doctor continued:

Doctor: *"Can I just check with him what tablets he's taking now, I think it's Metformin two tablets twice a day if we can check that one."*

Interpreter: (in Punjabi) *"what tablets are you eating when she asks let her know which tablets you are taking, are you eating Metformin two tablets twice a day?"*

Mr Shabir (in Punjabi): *"yes the ones they gave me afterwards I am eating two of them."*

Interpreter: *"do you not remember the name of them?"*

Mr Shabir: *"no I don't remember the name."*

Interpreter: (In English) *"right he can't tell you the name."*

Here we can see how the interpreter was interpreting verbatim what the doctor said, but the same degree of 'exactness' was not applied to what Mr Shabir was saying in response. It appeared that the interpreter was more inclined to ensure that the doctor's questions were answered by Mr Shabir and began introducing questions that had not been asked by the doctor *"do you not remember the name of them?"* Mr Shabir did not know the names of his medication, nor had he brought them with him, which did not help the situation. As an observer I felt uncomfortable watching and listening to what was going on as the

conversation continued and went around in circles creating further uncertainty over which tablets he was taking:

Doctor: *“Right Metformin is two...”*

Interpreter: *“He’s taking two twice a day.”*[He had picked this up from his previous conversation with Mr Shabir].

Doctor: *“Two twice a day, and there should be another tablet called Gliclazide em...”*

Interpreter: (In Punjabi) *“Are you taking Gliclazide?...it is a small tablet.”*

Mr Shabir: (In a questioning tone) *“the little one outside on the box it is written 80 percent”*

Interpreter: (in Punjabi) *“It will be 80 milligrams”*

Mr Shabir: *“yes 80 milligrams”*

The doctor did not wait for a response from the interpreter and asked the number of times he was taking Gliclazide:

Doctor: *“is that twice a day or...”*

Mr Shabir: (to the interpreter) *“there is one that is 20mg”*

Interpreter: (in Punjabi) *“right 20 mg”*

Mr Shabir: *“I take that too and another one...”*

Interpreter: (in Punjabi) *“in total how many tablets are you taking including all the different types?”*

In an attempt to establish Mr Shabir’s tablet regimen, the interpreter began to introduce his own questions *“in total how many tablets are you taking including all the different types.”* Unfortunately, this did not help clarify what Mr Shabir was taking and the confusion continued to grow:

Mr Shabir: *“All of them are different but..”*

Interpreter: (in Punjabi) *“no I’m asking in total how many are you taking?”*

Mr Shabir: *“one of them is for diabetes, it is 5mg, it is a big tablet and I take two tablets”*

Interpreter: (in Punjabi) *“you are talking about Metformin”*

Mr Shabir: *“the other ones the small ones”*

This dialogue continued in this fashion and took up much of the time allocated for this consultation. It had been several minutes since this particular conversation began, yet the doctor was still asking the same question:

Doctor: *“it was the Gliclazide the last time we increased the dose, now I’m just wanting to check how much he’s taking of that.”*

Interpreter: (in Punjabi) *“the sugar tablet called Gliclazide before the dose was lower then they increased it, is that right?”*

Mr Shabir: *“Before I used to take one in the morning and one in the night then afterwards they told me to take two twice a day and the blood thinning tablet I take at night separately. They also increased another of my tablets that was 80 grams, before I didn’t used to take that.”*

Interpreter: (in English) *“this is very confusing coz he doesn’t know the names of the tablets.”*

In what seemed like desperation, Mr Shabir attempted to involve me in the discussion so that I could help clarify what he meant:

*“I just don’t understand how to explain to you [laughing in a sort of desperate tone], the one tablet I take only one at a time...[turns to talk to me] yesterday sister I showed you those tablets the ones I take in the morning and at night...”*

I looked down and Mr Shabir turned back and again tried to describe the tablets he was taking to the interpreter and since he could only describe his pills in terms of what they looked like and the numbers on the pills’ packets he was unable to clarify specifically what medication he was taking.

Interpreter: (in English to the doctor) *“one tablet he takes at night time”*

Doctor: *“yes, that will be for the cholesterol”*

Interpreter: (in English) *“cholesterol one”*

Doctor: *“yes that’s fine, that’s fine em as far as I’m aware he takes an aspirin tablet in the morning, a cholesterol tablet at night, the Metformin tablet which should be two tablets twice a day, my only query is about the Gliclazide now. The last time he was here we had him taking just one tablet once a day, the plan was to gradually increase the dose of that and I just wasn’t sure how far we’ve got with increasing the dose whether he’s now taking the Gliclazide twice a day.”*

Interpreter: (rather abruptly in Punjabi) *“and now are you taking them twice a day the Gliclazide the small tablets?”*

Mr Shabir: *“yes I am taking them twice a day”*

Interpreter: (in English) *“yes he’s taking it twice a day.”*

This whole discussion was clearly very confused and finally Mr Shabir, seemingly under pressure, provided the answer that both the interpreter and the doctor sought; that he was taking Gliclazide twice a day. However, he had told me during his pre-consultation interview that he was taking only one Gliclazide a day. Despite the presence of an interpreter who was meant to ‘aid’ communication, the information exchange between Mr Shabir and the doctor was sketchy, incomplete and ultimately inaccurate. Moreover, it was clear to an onlooker, just by the length of the dialogues, that sometimes the interpreter was asking/saying more than the doctor had asked to be interpreted, and similarly, Mr Shabir was evidently saying more than the interpreter chose to interpret, yet neither the doctor nor Mr Shabir for that matter challenged him. By virtue of being the ‘middle man’ and the only one who could understand both languages Mr Shabir and the doctor had no choice but to rely on the interpreter.

Nevertheless, despite the lengthy dialogue, the doctor was no closer to finding out what was actually going on with Mr Shabir. The question is whether this discussion would have yielded a more accurate response from Mr Shabir had the interpreter also chosen to interpret verbatim what Mr Shabir said and not introduced his own questions into the discussion. This will be further explored in the following chapter when I describe another professional interpreter who did translate verbatim in both directions. It is worth pointing out that the doctor only received what the interpreter chose to convey. She would have been oblivious to anything that the interpreter did not choose to convey although she may have been aware that Mr Shabir was saying much more than was being interpreted.

The discussion then moved on to Mr Shabir’s blood glucose reading:

Doctor: *“the blood sugar level today is much better than it was when he was here three months ago.”*

Interpreter: (in Punjabi) *“you know your blood sugar level it is much better this time compared to the last time”*

Mr Shabir: (to interpreter) *“how much is it this time?”*

Doctor: *“so that’s good so I think increasing the dose of the Gliclazide has helped...”*

Mr Shabir: (in a frustrated tone of voice to interpreter) *“I want to know what number my sugar is at this time...”*

Doctor: *“...bring the sugar level down”*

Interpreter: (in Punjabi) *“just listen to her first, before they increased your dose of the Gliclazide tablet and because of that your sugar levels have come down”*

Doctor: *“so I think that’s helped...”*

It was clear that Mr Shabir was becoming increasingly frustrated as the dialogue progressed, yet the interpreter carried on interpreting for the doctor. He gave precedence to what the doctor said over what Mr Shabir said, so much so that when Mr Shabir repeated his question, the interpreter gave him instructions to wait and listen to what the doctor was saying. Relying on the interpreter at this point was hugely disempowering for Mr Shabir as the interpreter was not acting as a ‘voice’ for him. Unaware that Mr Shabir had asked any questions, the doctor continued to the next topic, his diet:

Doctor: *“Can you ask him if he’s made, had to make change in terms of his diet over the last six months?”*

Interpreter (Punjabi): *“in the last six months have you changed your manners of eating, have you changed anything in particular how you eat sugary foods?”*

The interpreter expanded the doctor’s question and asked Mr Shabir ‘how he ate (his) ‘sugary foods’, despite this not being part of the doctor’s question. Subsequently, Mr Shabir’s response addressed only this part of the question:

Mr Shabir: *“I don’t eat those kinds of things anyway ever since I have found out I have diabetes I don’t eat those kinds of foods.”*

The interpreter, it seemed, was a key player in determining the course and content of the discussion, to the extent that Mr Shabir was sidelined instead of being central to the interaction. It is also worth noting here that, at the beginning of the consultation, the doctor had began by addressing Mr Shabir in the first person but then changed to third person, for instance, “ask him” and “tell him” and made eye contact with the interpreter rather than with Mr Shabir. If all these subtle, but influential verbal and non-verbal factors are taken into account, it could be argued that it is hardly surprising that Mr Shabir refrained from raising his concern about his diarrhoea as the circumstances were barely conducive for him to bring up this matter.

Moving on through the consultation the doctor provided Mr Shabir’s average blood glucose readings which the interpreter conveyed to him along with the comments made by the doctor again that there had been a marked improvement since the last time he had been checked. This news appeared to hold little significance for Mr Shabir who was more concerned about the symptoms from which he suffered, some of which he actually did raise on this occasion:

Mr Shabir: *“Ok it may be much better but more than before the soles of my feet are burning”*

Interpreter: *“Right”*

Mr Shabir: *“before they burned a little like a normal amount but now they are giving off a lot of heat and my eyes are like they are swollen and hurt a little like..”*

Interpreter: *“Like you are feeling tired?”*

Mr Shabir: *“like I am very tired I am unemployed and yet I am so tired.”*

Interpreter: (in English) *“He feels burning in his eyes and tired eyes.”*

Mr Shabir attempted to raise the issues concerning both his burning feet, swollen eyes and about feeling more lethargic in general, yet only the concern about his eyes was conveyed to the doctor. Subsequently, the doctor asked a series of questions about his eyes but the issue of his feet along with his complaints about feeling tired were not conveyed to the doctor and hence she was unaware of these problems. This was just one of many examples of the way in which the interpreter was selective about the information he chose to convey. Why he did this and whether he was aware that he was doing this will become clearer during my post-consultation interview with the interpreter. The consultation continued with the interpreter



editing, omitting, ignoring and selecting the information he conveyed to the doctor while, in contrast, his attempts to interpret exactly what the doctor said remained rigorous.

Mr Shabir, once again, became resigned towards the end of the consultation and, for the most part, sat silently as the interpreter did most of the speaking. He did not attempt to raise any more of the problems he was experiencing. It appeared as though much of the consultation time was taken up discussing issues that appeared to hold little significance for Mr Shabir. The discussion about his eyes took up a substantial amount of time with the doctor trying to establish how long ago he had his last retinopathy test. Bringing the discussion about his eyes to a close the doctor said:

Doctor: *“the best way to improve that is to get the diabetes as well controlled as we can, so getting the sugar level nice and low, I would hope that as the diabetes improves it should get...”*

Interpreter: (in Punjabi) *“the best way is that your sugar level remains in control and if it stays in control then obviously your problems will automatically go away or get better”*

Patient: *“fine.”*

Towards the end of the consultation, the doctor advised Mr Shabir to further increase his current dose of Gliclazide, a decision which she made on the basis of her assessment that his average blood glucose readings had come down as a result of him taking two of these tablets a day. The doctor *thought* Mr Shabir was taking Gliclazide as was described to her earlier, yet this uncertainty did not affect her decision to alter the dose. The numerical result determining that his blood sugar was better than the last time was sufficient evidence to corroborate the information she obtained from Mr Shabir through the interpreter. Once the interpreter had told Mr Shabir that he was required to increase his Gliclazide his response was:

Mr Shabir: *“there are so many tablets of the same ones that I am taking and now they are asking me to take more...”*

Interpreter: *“they are the same tablets though”*

Mr Shabir: *“yes they are the same but they are telling me to take more”*

Interpreter: [no interpretation].

Mr Shabir's words once again were not relayed to the doctor and she assumed he was not objecting to the decision she had made. She asked the interpreter to write in Urdu on a piece of paper the name and dose of the pills that she had asked Mr Shabir to increase. Shortly after, the consultation came to a close; the interpreter handed the piece of paper to Mr Shabir and got up to leave. Mr Shabir said goodbye (in English) to the doctor and left the room with the interpreter.

To summarise this section of the chapter, it was not difficult to see how Mr Shabir's views about his consultations were, in part, shaped and informed by actual events that took place during the consultation. It was unsurprising that he felt that his trips to the hospital were a waste of his time and money given that most of the issues he attempted to raise were not addressed; for instance, the issue of his burning feet, his tiredness, his anxiety about taking too many medication and his concern that, despite his average blood glucose reading improving, he still suffered from symptoms. Relying on an interpreter in these instances did not facilitate communication but appeared to obstruct some of Mr Shabir's concerns reaching the doctor. Another important issue in all of this is that, because of the mis-conveying of information, the doctor may have also made an inappropriate decision about changing his medication. Why the interpreter chose to edit and convey only certain parts of what Mr Shabir said whilst ensuring that what the doctor said was interpreted more accurately and in full is something I explored in my interview with the interpreter the day after the consultation.

### **7.3 The interpreter's view**

As mentioned previously the interpreter had been interpreting in a professional capacity for over six years. He had migrated from Pakistan in the 1980s with his wife and children to join other relatives that were already living in the UK. My interview with the interpreter was conducted over the phone and we initially started to speak in English. However, I found the interpreter was more comfortable talking in Punjabi so we spoke in this language for most of the interview. He was friendly and willing to offer as much time as was needed to complete the interview. He told me, this was his main job and, that he interpreted for clients four or five times a week and most of his engagements were in the healthcare setting. I asked him:

NA: *"How did you find the appointment with your client went the other day?"*

Interpreter: *“that day there was a routine, so there was not much difficulty. I think it was a routine one.”*

He explained that interpreting during this consultation was fairly straightforward because no “special medical terms” were used thus it was not very “difficult”. I asked him what he made of the confusion over Mr Shabir’s tablets and he said:

*“Yes with the tablets that man did not even realise what tablets he was taking. Some people you know just know their tablets by the way they appear and they don’t know the names of their tablets...the thing is I take those same tablets, Gliclazide the ones they were talking about and luckily because I was taking them I knew what she was talking about.”*

The interpreter felt he was heavily involved during the consultation and his reason for this was:

*“This time I had been involved quite a bit just in case the patient came away thinking he was to take a different dose of medication than the doctor had suggested as that could be quite dangerous. So I have to be very careful and listen with care to what the doctor is saying and to explain back to them what the patient is saying.”*

Ironically, despite the interpreter’s best intentions, Mr Shabir came away from the consultation with the incorrect message, as I will illustrate further on in this chapter. Here the interpreter emphasised the importance of both listening to the doctor ‘carefully’ and ensuring that the patient’s response was then explained to the doctor. What was most notable was how the interpreter made no mention of the significance of listening to, or interpreting for the patient until I asked him:

NA: *“and how about listening to the patient?”*

Interpreter: *“oh yes definitely, for example I had to write down the details in Urdu for the patient about the dose of the tablets as he can’t read English.”*

Again, the emphasis was upon conveying the doctor’s message to Mr Shabir and not necessarily listening to what he had to say to the doctor. In fact, he went as far as to say that most of the Pakistanis he interpreted for, did not pay sufficient attention to what the doctor said and justified his view by saying:

*“If you are educated then you pay more attention right? You will also ask more questions of the doctors, right? That person will be more concerned*

*like I mean they will ask questions about long term consequences. And whoever is not so educated will come to these appointments get themselves checked, get a prescription and leave to go home."*

Arguably, the interpreter seemed to hold fairly strong stereotypical opinions about his uneducated Pakistani clients and, implied that they perhaps did not ask the relevant or appropriate questions that an educated person might ask. This revealed the kinds of expectations he held from consultations, particularly his perception of how patients should behave. His actions during the consultation could be seen to establish and sustain a paternalistic consulting style.

I asked the interpreter whether he felt he interpreted as accurately as he could:

*"I try my very best to do so but no one is perfect. I do try and interpret everything and I know that the interpreters who work with me do too and we particularly make sure that all information from the doctor is interpreted to the patient."*

Again, the interpreter made no comment about the importance of ensuring that the patient's concern reached the doctor until I asked for a second time in this interview:

NA: *"Ok how about what the patient says is it important for you to relay that to the doctor as well?"*

Interpreter: *"of course that is our duty obviously. If the patient says something then we have to make sure it reaches the doctor. But sometimes patients will not talk about the condition they came to talk about and sometimes they start going on about something else and the doctor needs to interrupt the patient and make it clear to the patient that they are there to talk about a particular condition and not to talk about any other, or maybe mention it at the end. So that happens sometimes. So what we have to do is extract certain points from what the patient is saying you know the useful things they are saying. So after identifying the useful points then I would tell the doctor what the patient's intended discussion was."*

It appeared that the interpreter had a clear idea of what patients should or should not be talking about during their encounters with their doctors. As was evident in this consultation, the interpreter relayed 'selected' parts of what Mr Shabir said. The interpreter's explanation for this was that he felt it was necessary to 'extract' and convey only the 'useful points' to the doctor. Here, the interpreter does not consider himself to be just a 'voice' between the patient and the health professional but an assessor and negotiator who created a 'relevant' discussion between the patient and the doctor. What is particularly questionable is how the

interpreter is able to judge what issues are actually important, given that he had no medical training.

Conversely, it is perhaps understandable why the interpreter felt obliged to take a more 'active' role. It may have appeared that the interpreter gave credence to what the doctor said over what the patient said, but this may have been because he was trying to present the patient in a favourable light. By limiting what Mr Shabir said he not only preserved the doctor's time but gave the impression that Mr Shabir's 'intended discussion' took into consideration the context for this appointment. In other words, the interpreter may have been 'saving face' and may have seen himself as helping Mr Shabir to look 'competent' in the consultation by editing out what he saw as irrelevant information.

The interpreter consolidated his point by saying:

*"It happens a lot ... our people talk in a roundabout way and not to the point so sometimes I have to stop them mid way whilst talking and tell them that whatever they are talking about is out of context."*

Indeed he felt that patients should be doing more to help themselves:

*"My view is that patients should be a little aware of their illness and the effects of it on their life as well and what the future may hold. But mostly our people don't know and when you tell them they are quite shocked. So I think there should be more awareness amongst them."*

In his view, not only did some patients lack correct judgement in deciding what issues to raise, but they also lacked fundamental knowledge about their condition. However, in his opinion, it was the patient's responsibility to acquire this knowledge and not something he expected to be delivered during diabetes consultations. It is fair to say that this interpreter held quite a critical opinion of some of the Pakistani patients for whom he interpreted. Understanding his opinion helps to explain why he acted the way he did in Mr Shabir's consultation. His behaviour was strongly influenced by his perceptions which explained why he prioritised what was said by the doctor over what was said by Mr Shabir. At no point during his interview did he express any negative views about health professionals.

The second interview I conducted after the consultation was with Mr Shabir and once more I visited his home.

## 7.4 Post-consultation interview with Mr Shabir

When visiting Mr Shabir's home for a second time, he immediately insisted on showing me the tablets he was taking so that he could clarify the confusion that arose during the consultation. I asked him if he had increased the number of Gliclazide tablets as the doctor advised him to do in the consultation. He said yes, but his understanding was that he was to take one Gliclazide in the morning and one in the evening. In the consultation, however, the doctor had advised him to take three of these tablets, one in the morning and two after his evening meal. The doctor had assumed he was already taking two tablets, at the time of the consultation, when he was actually only taking one. He also had the piece of paper to hand - the one the interpreter had written upon in Urdu. I asked him what it said:

*“On that it says I am meant to take one in the morning and one in the evening.”*

I looked at the bit of paper (which later during the interview his baby daughter chewed on then swallowed):

*NA: “on here it is written that you are meant to take one Gliclazide in the morning and two in the evening with food so you are meant to be taking three pills.”*

*Mr Shabir: “no I just take one and I understand that to be the case that I am meant to take one in the morning and one in the evening. Before I used to take this one once a day and then they increased it to twice a day. Now that's what I understood. So I understood that I am meant to take one in the morning and one in the evening”.*

He seemed disinterested in looking at the bit of paper and I wondered if he had even read it. One explanation for this could be that he may have been illiterate and was too embarrassed to say so. Mr Shabir had misunderstood the advice the doctor and indeed the interpreter intended him to receive and one could argue it was fortunate that he had, since he may have been at risk of taking too much anti-diabetic medication which could have put him at risk of an hypoglycaemic attack. Even more concerning was that Mr Shabir was not taking the dose of Gliclazide that the doctor had understood him to be taking in the first place so the confusion during the consultation was never resolved. In the broader context of his life, all of this mattered very little to Mr Shabir because, as the next quote demonstrates, in effect, he was making his own decisions about how much medication he took. Mr Shabir had mentioned to me in his pre-consultation that he had suffered from a cold:

Mr Shabir: *"I have reduced the other ones (Metformin)"*

NA: *"but they are also for your diabetes?"*

Mr Shabir: *"yes they are but I am taking less because of the cold I had ."*

NA: *"why?"*

Mr Shabir: *"look sister I can't take too many tablets because of my cold it's just too much. You know baji whenever I eat those tablets after a little while I feel like I am going to be sick. I get that kind of feeling"*

NA: *"why did you not discuss that at the appointment?"*

Mr Shabir: *"it doesn't matter, firstly I didn't remember and secondly I thought to myself that I have been eating these tablets right from the start and they [health professionals] would just say that he didn't have a problem with them before and now suddenly I do."*

He told me he had cut down on the amount of Metformin he was taking several weeks prior to the consultation, and was not taking two of these tablets in the morning and two in the evening as the doctor was led to believe. Mr Shabir purposefully chose not to disclose this information during the consultation and gave two reasons for this; that he had forgotten and felt that he might be judged if he told 'them'. With Mr Shabir feeling this way and the interpreter, at times, discouraging Mr Shabir from asking questions, the consultation was hardly a conducive environment for him to admit that he had altered his dose without first consulting with a doctor.

Then, there was the issue of his long standing diarrhoea and why he felt he could not discuss this concern with the doctor:

Mr Shabir: *"oh yes I just forgot about that I didn't remember to talk about it. I was so busy talking about other things. My wife asked as soon as I came back but I had forgotten to ask."*

Given how the encounter between Mr Shabir, the interpreter and the doctor had unfolded there was a certain irony to his comment. It also seemed like Mr Shabir had re-constructed his narrative, partly because he was 'saving face' with me and, arguably, it was easier to say that he had forgotten than to admit his own inability to get himself heard in the consultation.

However, Mr Shabir held little hope of ever achieving a successful resolution, following excerpt reinforcing what he had said in his pre-consultation interview:

NA: *“but you have talked about it several times before?”*

Mr Shabir: *“sister I have been talking about it so many times with the doctors, and how many more times can I tell them.’ It has made no difference. The same with my feet I feel a lot of burning and heat from them.”*

On this note I asked Mr Shabir a more general question about how he felt the consultation went:

*“I felt it went well this time. That is because they spent time with me and checked me over.”*

Similar to other respondents in this study, Mr Shabir told me that he thought this consultation was better than some of his previous ones. Again, I was inclined to think that because I had watched the interaction, Mr Shabir, like others, found it difficult to voice criticism (if any) in case it conflicted with my opinion and made him ‘look ungrateful’ in my eyes. I further probed:

NA: *“did you feel you understood everything the doctor was saying to you?”*

Mr Shabir: *“yes more or less I understood everything that was being said.”*

NA: *“did you ever feel that any of the things discussed needed to be clarified or discussed further?”*

Mr Shabir: *“no it was fine.”*

From his comments, it initially seemed Mr Shabir was very much in the dark about all the miscommunication which had taken place during the consultation and was oblivious to the fact that the interpreter had heavily edited what he had said.

I asked him whether he felt that everything he discussed with the interpreter was being passed on to the doctor and his response was:

*“Yes that was fine. But the thing is I couldn’t understand what was being passed on, you were sat there you could understand better than me but as far as I can tell everything was being passed on.”*



In a way Mr Shabir had little choice but to take a leap of faith particularly as he was reliant/ dependant on both the interpreter and the doctor for different reasons. However, things were a little more complex than this. During the consultation, I had assumed that Mr Shabir expected and, indeed, wanted everything he said to be relayed to the doctor but this was not necessarily the case. In the consultation Mr Shabir made a comment in response to the interpreter telling him that he had to increase his medication:

*“So much medication are they trying to kill me” [excerpt from consultation]*

I asked him whether he thought his comment was relayed to the doctor and he said:

*“I said that to the interpreter, I had no intention of the doctor knowing. I said to the interpreter jokingly ‘are they trying to kill me.’”*

It seemed, Mr Shabir did not expect or indeed wish for everything he spoke of to be interpreted by the interpreter including this ‘humorous remark’. Therefore, Mr Shabir expected the interpreter to do some editing and use his own judgement to establish what should or should not be conveyed to the doctor. Within the triadic interaction it seemed there were ‘other’ interactions going on which were kept invisible from the doctor. In retrospect, the interaction between the interpreter and Mr Shabir was considerably less formal than the interaction between the interpreter and the doctor.

There is no doubt that matters such as this indicate some of the complexities and intricacies inherent in interpreted consultations. I gained the impression that familiarity between the interpreter and Mr Shabir partly contributed towards Mr Shabir being disempowered during the consultation.

I asked him whether he perceived the consultation to be of an adequate length:

*“When we can’t speak openly in our language we only need 4 or 5 minutes there and then come back home. Like now I can answer all the questions you are asking and I can explain things. I can go and pick up prescriptions as you don’t have to say much. I had an appointment with my own GP and he said next time I would be seen by a different doctor but how can I be seen by another doctor when I can’t even explain to them. Getting an interpreter is a problem as it takes up to two weeks to arrange for one. At the moment I am unwell I just didn’t go to see the GP. I take Paracetamol and Ibuprofen. I just do everything at home as they will likely give the same”*

In answering my question many anxieties came to the fore for Mr Shabir. It was clear he experienced difficulties arising from not being able to speak English, not least because he found it difficult to arrange an interpreter as and when he needed one. He had resorted to dealing with some of his illnesses by self-medicating at home. Moreover he was nervous about seeing another GP which further compounded his anxiety. Much of the remainder of this interview was taken up by Mr Shabir talking about his financial concerns. It was clear that, in the face of such adversity, his diabetes was a minor concern for him.

The final component to this case study was the interview with the doctor which was conducted over the phone.

## 7.5 The doctor's view

The doctor had asked me to call her early in the morning before she began her medical round on the ward. I had a small window of time in which to talk to her so I immediately began by asking her questions about the consultation.

I asked her what she hoped to achieve in advance of seeing Mr Shabir:

*“em...ooh...I suppose I wanted to make sure he had good understanding about eh...his diabetes, particularly in relation to his diet, em that he was doing the right things in terms of diet, em...that he understood what tablets he was taking and eh...and...who, eh basically understood how that I suppose affected his sugar control and then eh, understood the need for any changes in medication...”*

From the above excerpt it seems that the doctor could have been referring to pretty much any patient considering the ‘mechanistic’ way she answered the question. She said she had wanted to ensure that Mr Shabir had a ‘good understanding’ of his diabetes, yet in the consultation there was hardly an in-depth exploration of how well he had understood how his dietary regimen and tablets affected his blood glucose control.

When I asked her how she thought the consultation had gone, she replied:

*“Em...I think initially it was very...it was pretty difficult coz it was quite clear, eh...initially there was some confusion about medication, em I think once we got through that bit of things, em...I think overall he seemed to go away I think with all the sort of...in light...of under...understanding and things.”*

Similar to the interpreter and Mr Shabir, she acknowledged that there were difficulties in confirming what medication Mr Shabir was taking but in her own words they “*got through that bit of things*” implying that she thought, that the confusion was eventually resolved. Saying this, it needs to be taken into account that the doctor’s judgement was likely to be have been based upon what she was ‘hearing’ back from the interpreter who had mostly provided her with definitive answers despite the uncertainty that arose from his conversations with Mr Shabir. Judging from the previous excerpt, the doctor had gained the impression that Mr Shabir had understood most of what was discussed when (as can be seen from Mr Shabir’s post-consultation interview) the main message about his medication had been misunderstood. I asked the doctor a general question about whether and how she was able to establish if patients in triadic interactions understood what was being said:

Doctor: “*yeah I suppose from non-verbal cues or, you know at the end of it asking, you know, have you got any questions, you know, or at different points in the interview, you know, or at different points in the interview.*”

NA: “*what kinds of non-verbal cues?*”

Doctor: “*Em...I don’t know like nodding of the head...em mainly I suppose and good eye contact.*”

For the doctor, a ‘nodding of the head’ together with ‘good eye contact’ was a way of establishing understanding. On another note, it was unclear how this doctor established understanding through ‘good eye contact’ when, during the consultation involving Mr Shabir, she had looked at the interpreter when she talked.

The next set of excerpts illustrate some of the doctor’s perceptions of the interpreting which had occurred during the consultation:

Doctor: “*I certainly got the impression that the interpreter was pretty good in terms of, you know, relaying my information to him and relaying things back...*”

The doctor, like Mr Shabir, did not doubt the interpreter’s translational skills. Indeed, the interpreter ensured that the doctor’s questions were answered promptly; giving the impression that information was efficiently being transmitted. Although the doctor was unsure whether this interpreter was professional or a family member/friend she commented that she preferred to deal with a professional interpreter:

*“When it’s families there are often other agendas and often I think that sometimes it’s easier if it’s a professional interpreter because they’re in theory just translating exactly what you’re saying. When there’s family you do sometimes find there’s others agendas and you know information that goes back and forward maybe it’s sort of tainted a bit by the family member.”*

It was assumed that professionals interpreted everything ‘exactly’ whereas family members imposed their own agendas upon the interpreting process. However, as illustrated earlier, this professional interpreter certainly did not interpret everything that was being said and indeed seemed to bring his own agendas to bear in the consultation. Health professionals’ views on interpreters will be further explored and discussed in the following chapter.

I asked the doctor how she felt Mr Shabir was managing his diet and she told me that she had not delved too deeply into this during the consultation as she trusted that the Punjabi speaking dietitian (referred to earlier) was taking care of that aspect of Mr Shabir’s care. Her view was also that, because Mr Shabir could communicate in his first language, these consultations were likely to be better as there was one less barrier with which to contend:

*“Language definitely adds an extra barrier. I think there’s no doubt that we’re relying, as I say, a lot on non-verbal cues, we’re relying on interpreters, you know, giving the information and sometimes, you know, it’s quite sort of medicalised sort of information we’re asking them to pass on. Obviously we don’t know exactly what is being translated and exactly what’s coming back and I think it often tends to be a one way conversation...I think we’re very lucky to have [name of the Punjabi speaking health professional], that’s made a huge difference to the department as you know we are left feeling a little bit in the dark as to whether the message has got through and whether there were any additional sort of issues that weren’t addressed.”*

Finally, I asked her what she thought the main messages were that Mr Shabir had received:

*“Em...I think...well he took away that the diabetes was much better controlled than it was before, that he was making a good effort with lifestyle and dietary change, that the change in his medication had also helped him through the diabetes and although things were improving they still weren’t absolutely perfect, which is why we wanted to increase the medication a little bit more. But eh hopefully overall he was taking away a fairly positive message about it...”*

Mr Shabir, as illustrated earlier, held a different perspective about his interaction with the doctor. He was unhappy about the advice to further increase his medication and demonstrated his disagreement by making his own choices about how much medication he

took. Moreover, on being told that his diabetes control had improved he barely took this as a 'positive' message because his symptoms had not improved, something he had been unable to convey to the doctor.

## 7.6 Summary

In this chapter many of the issues that arose were also found in the case studies illustrated in the previous chapters. Like other patients, Mr Shabir held limited expectations about his consultations. Mr Shabir suffered from multiple health problems yet, like other patients, he did not raise all his concerns during his consultation. Despite the difficulties in communication I observed in the consultation, Mr Shabir, like other patients in this study, also perceived his consultation to have been better than previous ones. This case study also revealed how the interpreter's interaction acted as a barrier to promoting effective communication between Mr Shabir and his doctor. During the consultation the interpreter edited, omitted, misconveyed information between the two parties. Part of the reason for this was because the interpreter felt he was also there to direct the conversation in a way that he deemed appropriate. Since Mr Shabir's health concerns largely remained unaddressed, partly because of how the interpreter interpreted, but also because Mr Shabir did not raise all his issues, he continued to suffer from problems which could potentially become more serious in the future. Mr Shabir's doctor considered the consultation to have been unproblematic and appeared unaware of how much misinterpretation had actually taken place during the interaction.

In the following chapter, I will illustrate and describe a further two case studies involving interpreters (one professional and one lay). I will compare the different styles of interpreting adopted by different interpreters and also provide examples of when interpretation appeared to have facilitated communication between a patient and their provider. From this chapter, I will take forwards and further develop the finding that by simply addressing one barrier in isolation, in this case language does not necessarily mean that other, just as important, barriers are overcome. In the following chapter I will show how the patient-interpreter relationships outside the consultation setting may facilitate and/or hinder effective communication between patients and health professionals. I will also further elaborate on health professionals' views about working with an interpreter, both lay and professional.



## **CHAPTER EIGHT: MR RAZA AND MRS SALMA**

In this findings chapter, I will present two case studies involving interpreters. The first case study involves Mr Raza who was accompanied to his consultation by a professional interpreter and, who acted very differently to the way Mr Shabir's interpreter had done in the consultation that I have just described. The second case study involves Mrs Salma who was accompanied by a lay interpreter and will serve to illustrate, amongst other things, how the patient-interpreter relationship outside the consultation can affect what goes on during the consultation interaction. By beginning this chapter with another case study involving another professional interpreter and comparing with the previous example, I will highlight and explore how different interpreting styles can impact and influence communication between patients and their healthcare professional. I will suggest that by virtue of serving a close-knit Pakistani community, these interpreters were often faced with dilemmas which sometimes force them to make choices and difficult decisions. Implicit in these choices and decisions are how they viewed themselves in relation to the community to which they belong. Although I will be describing two case studies, these will not be as detailed as the one presented in the previous chapter, as I will just be drawing out findings which are most salient to my analysis. I will now describe the case study involving Mr Raza.

### **8.1 Mr Raza**

Mr Raza had migrated from Pakistan to the UK two years ago together with his wife, four daughters and two sons, in the hope of securing a 'better' future for his children. He told me he worked as a chef in the evenings and would return home after midnight and have his dinner then. Despite living in a small and seemingly over-crowded flat, he talked about how grateful he was to be living in Britain, and being able to access 'free' health services. He talked a little about his religious beliefs and told me how proud he was that his family still followed the religious and cultural values that they had been brought up to respect in Pakistan. Mr Raza was educated up until the end of high school. Mr Raza said he spoke little English and that a professional interpreter accompanied him to most of his medical appointments. Occasionally his daughter would accompany him although she had only been living in the UK for the same length of time as him. He was attending an English language course and hoped that he would eventually be able to attend his consultations without an interpreter. I interviewed Mr Raza, in Punjabi, two days before his consultation at the hospital.

### 8.1.1 Pre-consultation interview with Mr Raza

When I arrived at his flat, I was led into the lounge by his sister-in-law who also lived with him. Mr Raza, a tall and slim man, was wearing trousers and a shirt and was watching a cricket match between India and Pakistan on the television. He stood up to greet me and asked me to sit on the sofa a few yards away from him. He pulled out a chair from under the dining table and sat on it. After he had sat down, Mr Raza gave his full attention to the cricket match he was watching and I sat quietly, listening to the comments he was making about the match. Eventually he muted the volume on his TV and turned towards me to signal that he was ready to talk. One of Mr Raza's daughters joined us in the room and, for most of the interview sat quietly in the room. At one point Mr Raza asked her to bring his medication through to show them to me. I began the interview and told him that I would mainly be asking questions about his experiences with the healthcare services. At this point, he chose to tell me how he thought that the UK health services were good because all patients were treated equally and, with respect, something which he claimed, did not happen in Pakistan's healthcare system. It seemed that he was keen to say positive things about the care he had received in this country and I began to wonder whether he actually thought I worked for the NHS.

Mr Shabir emphasised how he and his family were much "happier" since they had come to the UK because there were better prospects here, in terms of education and employment, for his children. He also said that he felt his life was more 'safe' and 'comfortable' for him and his family here than it was in Pakistan. I further asked Mr Raza:

NA: *"You said that life is comfortable, what does that mean in terms of your diabetes?"*

Mr Raza: *"My diabetes is well controlled it is first class. Thank God."*

However when I asked him why he was attending the hospital, Mr Raza contradicted his claim that his diabetes was 'well controlled'. He told me he was booked in for two consultations at the hospital, one with the DSN and the other with a dietitian. He said that the doctor with whom he had last consulted had considered starting him on insulin therapy as his average blood glucose readings had been high. The nurse was to assess his progress after six weeks and pass on the details to the doctor and a dietitian appointment had been set up to enable him to discuss any issues he had with his diet. The following excerpt gives an example of Mr Raza's inconsistent views regarding his diabetes control:



NA: *“what do you understand about your appointments on Monday can you explain what’s going to happen?”*

Mr Raza (in Punjabi): *“The appointment is with the nurse and the dietitian. When I went there (hospital) the last time, there was a lady doctor and she said to me that my sugar was a bit high and how she wanted me to start insulin. But she went on to say that she would confer with a senior doctor and then write to me to tell me whether I needed to start insulin or not. So when I went again...no I got a letter and it was an appointment with the nurse and I showed her my (daily) results and she said my results were absolutely fine and said that ‘in my opinion you don’t need to begin insulin’. After she conferred with the doctor who said that they would give me six weeks and then after that they would decide about insulin. So this is my next appointment.”*

In recounting the order of events and discussions that had taken place, Mr Raza represented himself as having played a minimal role in any of the decisions and debates that had taken place regarding insulin therapy. For instance, his comments suggest that two of the main conversations had been closed discussions between health professionals who subsequently informed him of their decisions. Nor did he voice any personal opinions or thoughts he may have had but rather, he, described what he perceived to be the opinions and views held by others. I asked him whether he thought his blood glucose levels were high:

Mr Raza: *“I felt it was ok but they said it was slightly above seven, they said that the average should be below seven. When I went before [for a routine check up] it was below seven. I have probably been eating too many biscuits but am not sure why it is high. Sugar does go up and down you see.”*

Although Mr Raza acknowledged that his sugar levels were probably ‘high’ he explained that the ‘slight’ increase may have been due to his ‘eating too many biscuits’ implying that he thought that his blood sugar levels were prone to fluctuations. Mr Raza wanted to avoid insulin therapy for as long as he possibly could and, although he depicted himself as a patient who deferred to the decisions made by health professionals, he did express some resistance in the context of my interview with him:

NA: *“Do you always agree with whatever decision the doctor makes?”*

Mr Raza: *“yes and I should, but once I did ask the doctor that I wanted to avoid insulin, as once you begin it is not possible to come back off it”*

NA: *“what was the doctor’s reaction when you told him that you wanted to avoid insulin?”*

Mr Raza: *“He increased a tablet and with that it remained in control and still is in control.”*

Again it can be seen how Mr Raza contradicted himself when he said his blood sugars were “still in control” with what he said in a quote illustrated earlier “not sure why it is high”. It seemed that Mr Raza used the notion of ‘control’ to describe how his diabetes was balanced overall. If it were slightly “high” then this was a temporary fluctuation which rendered little effect upon the ‘control’ of his diabetes. In another part of his interview he said:

*“The way they told me to I took my medication and controlled it myself, I controlled everything so thank God everything is under control.”*

Although he was reticent about starting insulin therapy he seemed to know that at some point a transition to insulin would be necessary and inevitable:

*“I will accept it as it’s for my own well being. If my sugar is not controlled with the tablets then the alternative is insulin and so I should go on that.”*

He continued:

*“They said that it was quite high, above the average according to the test. They said that we want you go on to insulin so your sugar remains low and doesn’t go high so that you have a longer life to live. They said that life and death is in God’s hands but with the insulin your quality of life will be better.”*

During the interview, Mr Raza appeared to be working through his thoughts and acknowledged that his blood glucose levels were ‘quite high’ whereas before they were only ‘slightly high’. He went on to rationalise how insulin therapy may give him a ‘longer life’ but reverted to a fatalistic view that the time of one’s death was pre-determined by God. Nevertheless, he still hoped that the outcome of his next consultation would not involve him starting on insulin:

NA: *“let’s see what the nurse tells you on Tuesday, but from what you’re saying you don’t want to go onto insulin?”*

Mr Raza: *“Yes I would rather not take insulin and that my result remains good, I really hope that my result is ok and with the wish of god I don’t need to go onto insulin.”*

When I asked Mr Raza whether he was suffering any other health problems he told me:

*“I have tablets for gout as my toe was really swollen. I had to take five tablets for five days and with that my sugar went really high, like very high. I’ve had gout for a while but I am on the medication permanently now. They gave it to me before temporarily, but now they have given it to me permanently.”*

Gout, which arises from poor blood circulation in the limbs, is considered to be a complication of poorly controlled diabetes (Fox and Mackinnon, 2002). However, Mr Raza did not see his gout as being a consequence of his worsening diabetes. Instead, he felt that the medication he was taking for it was causing his blood glucose levels to rise, inferring that he thought he might be able to bring it back down if he stopped taking it.

As can be seen, Mr Raza’s account contained contradictions which speak to the complexities involved in the thought processes and the emotional dilemmas involved in facing treatment changes. He appeared to think that his diabetes was ‘controlled’, yet he acknowledged that his blood glucose levels had been, and were still likely to be, high. He seemed hopeful that insulin therapy could be avoided in his next consultation, yet he claimed he was ready to accept the decision to move onto insulin if necessary ‘for his own well being’. Understandably, his thoughts about beginning this treatment were shaped and influenced by a complex and sometimes contradictory array of factors. Some of these factors included his knowledge that his blood glucose levels were currently high and his understanding that insulin could ‘improve the quality of his life’ but he also drew upon a fatalistic view. He considered the effects of his gout medication and eating too many biscuits to have adversely affected his blood sugars, suggesting that these causes could be dealt with and his blood sugars could be restored to normal levels.

## **8.2 Mr Raza’s interpreter**

During the interview, I established that Mr Raza was usually accompanied by the same interpreter who had interpreted for Mr Shabir (see previous chapter). Mr Raza had expected to be accompanied by the same interpreter but this did not happen. Interpreting and Translating Services (ITS) assign interpreters to clients a few days before their scheduled appointments, and endeavour to match the gender of the interpreter with that of the client, but depending on the availability of the interpreters, they are not always successful. On this occasion, Mr Raza was accompanied by a female interpreter who had interpreted for him once before.

The interpreter was in her early forties and had been interpreting in a professional capacity for over four years. She was born in the UK and had lived here for most of her life. In her early teens, her parents had sent her over to Pakistan to live there for a year so she could become familiar with Pakistani culture and values. As a result of this experience, she could converse fluently in Urdu and Punjabi as well as English. The interpreter had told me that most of her work involved interpreting in medical consultations. Her mother-in-law was diabetic and she often accompanied her to her consultations which suggested that she had some knowledge of diabetes. On the day of the consultations she arrived before both Mr Raza and I, and greeted Mr Raza as he arrived but no ‘small talk’ ensued. Instead she spoke to me and asked me questions about my research. Shortly after, the nurse asked us to come into the consulting room.

Since the interpreter’s style was similar in both the nurse and dietitian consultations, for the purposes of this chapter I will only focus on data from one of these. I have chosen the nurse’s consultation as the main discussions around insulin therapy occurred in this setting. The nurse involved in this consultation was in her sixties and was experienced in consulting with Pakistani patients. Moreover, she had been involved in research that explored ways in which health outcomes could be improved for ethnic minority patients with diabetes.

### **8.3 The consultation**

The nurse led us into a narrow room, in which there was a desk, a sink and four chairs. The desk was located against a wall and the nurse sat on a chair next to it, facing towards the two chairs in which the interpreter and Mr Raza were seated. My chair was next to the sink and about three feet behind the nurse’s, so I was facing her back but could see the faces of the interpreter and Mr Raza. This consultation lasted 24 minutes which was longer than all the consultations involving doctors observed in the study.

The consultation began with the nurse summarising a discussion she and Mr Raza had had previously:

Nurse: *“So the last time we met em we talked about you may be having to start insulin.”*

Interpreter (in Punjabi to Mr Raza): *“she is saying that when you last met she maybe mentioned that you may need insulin.”*

Mr Raza (in English): “yes”

Nurse: “*but you felt you wanted to try and exercise and improving your diet.*”

Interpreter (Punjabi): “*you said that wanted to try and control your condition by exercising and by the way you eat and drink*”

Mr Raza (in Punjabi): “*I asked for a time of six weeks.*”

Interpreter (In English to nurse): “*And you had said that you would give him six weeks.*”

Nurse: “*yeah and have you succeeded at that?*”

Interpreter (Punjabi): “*she is saying have you been successful?*”

Mr Raza (Punjabi): “*No*”

Interpreter (in English): “*No.*”

This dialogue was surprising to me as up until now I had thought it was the health professionals and not Mr Raza who had requested the six week period. Looking back at the pre-consultation interview this could have been a case of miscommunication between Mr Raza and I, in which I had perhaps gained the wrong impression. He had previously said to me “*she told me that they would give me 6 more weeks*” (page 4) and I had presumed this decision had been made by the health professional. During his pre-consultation interview, Mr Raza did not tell me some of this contextual information and this, together with his seeming propensity to represent himself as a ‘passive’ patient, may explain why and how this misunderstanding arose.

As the consultation progressed, it was clear that Mr Raza was not as passive as I had expected him to be based on the impression I gained from my pre-consultation interview with him. In the consultation I observed he appeared to take an active role. The interpreting style of Mr Raza’s interpreter was different to Mr Shabir’s interpreter and may in part, have influenced the way Mr Raza behaved during his consultation.

The interpreter appeared to be rigorous ensuring that both the nurse’s and Mr Raza’s talk was conveyed accurately. Unlike Mr Shabir’s interpreter, who seemed to only favour interpreting verbatim the doctor’s speech, she made equal effort to interpret for both parties.

Following on from the previous consultation extract, Mr Raza explained why he had been unsuccessful in lowering his blood glucose levels:

Mr Raza (Punjabi): *“the reason for that is because my foot was swollen on the 28<sup>th</sup> of last month.”*

Interpreter: *“He said he hasn’t been successful because on the 28<sup>th</sup> of last month he had swelling in his foot.”*

Nurse: *“right.”*

Mr Raza (Punjabi): *“then I went to the doctor on the 28<sup>th</sup>.”*

Interpreter: *“he went to see his GP on the 28<sup>th</sup>.”*

Nurse: *“right”*

Mr Raza (Punjabi): *“He gave me medication for the swelling to come down but he said that my sugar will go very high”*

Interpreter: *“He gave him some em put him on some medication that would actually bring the swelling down but it would increase his sugar levels”*

Nurse: *“oh right.”*

Mr Raza raised the issue of his gout and the interpreter, for the most part, offered a literal interpretation of what was being said. She spoke slowly and carefully which enabled Mr Raza the time and space to say what he wanted to say. In justifying why his results had not improved, Mr Raza explained that the treatment he had received from his health professionals had meant that he had been unable to control his blood glucose levels. Understandably, it was important for Mr Raza that the nurse was aware of the GP’s warning, enabling him to abdicate any responsibility for his high readings. Also, he may have wanted to highlight that his high readings were due to a temporary factor and hence might not require a permanent solution (i.e. insulin).

Although the interpreter appeared to be interpreting most of what was said, she actually missed interpreting some information conveyed by Mr Raza. Mr Raza had said *“he (GP) said that my sugar will go very high”*. However, in interpreting this information back to the nurse the interpreter did not make it clear that it was the GP who had said this and instead said *“but it would increase his sugar levels”*, hence the nurse could have understood this as

being Mr Raza's experience or perception of taking the medication. Since the interpreter gave the impression of competency when conducting her role, this subtler and unexpected form of misinterpretation may have remained unnoticed during the observation. These interpretational errors may have impacted upon the course of the consultation but it did not discourage Mr Raza from voicing his concerns, in part because he was not aware of them.

The nurse acknowledged that Mr Raza's gout perhaps contributed towards raising his blood sugar levels but she had come to a different conclusion than the one presented by him:

Nurse: *"so were you not able to walk?"*

Interpreter (Punjabi): *"Could you not walk?"*

Mr Raza: *"It was difficult; it was very difficult [the interpreter nods and the nurse acknowledged this as a yes]."*

It seemed then that the nurse may have seen Mr Raza's inactivity and not the medication per se as giving rise to his high blood glucose levels.

It is also worth noting that this health professional talked directly to Mr Raza in the first person unlike Mr Shabir's doctor, who had mostly referred to him in the third person. Moreover, she made eye contact with Mr Raza and not the interpreter when she talked. In another attempt to convince the nurse that the medicines caused his blood sugar levels to rise, Mr Raza pulled out a diary from his jacket pocket in which he had recorded his readings during this period. He suggested that even after stopping the medication, the effects of it were still present in his blood, which had adversely affected his readings.

Mr Raza's interpreter seemed to have deployed techniques and strategies which informed her style of interpreting in an effort to ensure that both Mr Raza's and the nurse's 'talk' was exchanged fully and accurately. Although there were slight inaccuracies with the way the interpreter translated information, as illustrated previously, on the whole she was consistent in providing accurate translations. In the following section, I will provide some examples which demonstrate some of the techniques she used.

### 8.3.1 Creating spaces and gaps

The following dialogue is a discussion around Mr Raza's medication intake during Ramadan:

- (1) Mr Raza (Punjabi): *"I am fasting"*.
- (2) Interpreter: *"He started fasting, it's Ramadan."*
- (3) Nurse: *"Oh Ramadan."*
- (4) Mr Raza: *"I just wanted to say that when I check my sugar level in the evening, I*
- (5) *spoke to the doctor and she said not to take this tablet and I don't take them."*
- (6) Interpreter (English): *"He actually consulted with his GP first before he started*
- (7) *fasting [interpreter pauses]."*
- (8) Nurse: *"Good."*
- (9) Interpreter: *"and his GP had said that he could fast but there was one*
- (10) *medication that he was not to take."*
- (11) Mr Raza: *"Avandia and Metformin, I don't have to take this in the morning but*
- (12) *can take them in the evening."*
- (13) Interpreter: *"Avandia and Metformin, normally he takes it in the morning but*
- (14) *wasn't to take the morning he takes them in the evening."*

The above dialogue illustrates how the interpreter ensured that most of the information spoken was accurately conveyed, although at one point she did provide contextual information not offered by Mr Raza as can be seen in line 2, *"it's Ramadan"*. She spoke clearly and slowly creating sufficient opportunity for the person to acknowledge what she had just said, before moving onto the next piece of information. This is evident in lines 6-10 when the interpreter managed what Mr Raza had said by translating it in two stages. Her pause (line 7) made it clear that she had more to say. These spaces and gaps enabled her to interpret almost sentence for sentence.



### 8.3.2 Making and breaking off eye contact

The other strategy, which was also evident in the above dialogue but which I will focus upon in the next quote, was the way in which the interpreter made and broke off eye-contact. She would accept a certain amount of information before discouraging the speaker from talking further, so she could begin interpreting what had just been said. She did this by occasionally glancing over to the ‘client’ who was waiting for the information to be passed on to them which worked as a cue for speakers to allow interpretation to begin. This meant she could manage small blocks of information ensuring that most of what was said was conveyed fairly accurately. The following dialogue provides an example of this strategy:

Nurse: *“Today I’ll take a blood sample and it’s called your HbA1C, it’s the long term average sugar level [interpreter faces away from nurse and towards Mr Raza].”*

Interpreter (Punjabi): *“She said that she’ll take your blood sample [interpreter turns towards nurse to speak to her], so could you please repeat that again?”*

Nurse: *“HbA1C”*

Interpreter (English): *“HbA1C. [Speaks to nurse] this is the name of the test?”*

Nurse: *“Yes”.*

Interpreter: *“This is the name of the test and it means that it’s the sugar for long term not for the time being. Do you understand that?”*

Mr Raza: *“Yes.”*

Interpreter: *“It records long term.”*

Mr Raza: *“It records everything from the past as well.”*

Interpreter: *“Yes.”*

Mr Raza: *“I know that.”*

Here we can see how the interpreter actively broke down the information provided by the nurse into smaller segments. She also asked the nurse to repeat and clarify information before interpreting it to Mr Raza. Her manner of making and breaking eye contact encouraged both the nurse and Mr Raza to speak in small sentences and, avoid any overlapping speech. She clearly commanded control over the way in which the dialogue was structured. Mr Raza appeared to understand the test (HbA1c) to which the nurse referred as

he nodded his head when she talked, but the interpreter did not acknowledge this and persisted in interpreting verbatim. Referring back briefly to the case study involving Mr Shabir, his interpreter had explained that patients may nod their heads sometimes when clearly they have not understood what has been said. It seemed as if Mr Raza's interpreter may have been trying to prevent any such misunderstanding from arising hence she ignored the fact that he did nod his head and continued to interpret.

## 8.4 Other non-language barriers

Arguably, the language 'barrier' appeared to have been addressed in this consultation because the dialogue was on the whole fluent between the three parties. Although there appeared to be some evidence of misinterpretation, this did not cause any major misunderstandings which influenced any treatment decision. Presumably, then, this consultation could be considered 'successful' if 'communication' is simply about being able to talk with each other. In actual fact, these interactions are far more complex and having an impartial 'voice' through which to communicate, does not necessarily equate to frank and 'open' communication. In previous chapters I have discussed how patients sometimes did not raise information that may have been relevant to their consultation. During the consultation, Mr Raza and the nurse discussed issues which related to him observing fasts during Ramadan. Mr Raza had told the nurse that he would break his fast should his sugar levels become low, in his post-consultation interview with me he told me the opposite. The following interview quote is from my post-consultation interview with him:

NA: *"When you check your blood during the day and it happens to be low, would you break your fast?"*

Mr Raza: *"It depends on how I feel at the time and if I happen to feel really bad then I would break it."*

NA: *"If you are feeling unwell?"*

Mr Raza: *"Yes If I am feeling unwell but if my sugar is low when I check it and I am feeling alright then I won't break the fast."*

He may have told me this because by, insisting that he make every effort to sustain his fast, he was trying to present himself as a 'good' Muslim to me. Nevertheless, had he shared this view with the nurse then it would be likely that she would have explained and warned him against the risks and dangers of not taking the appropriate action.

So far, in this case study involving Mr Raza, I have illustrated how an interpreter may facilitate communication by ensuring that information is transmitted accurately in both directions. Although this helped address the language barrier and minimised the risk of any miscommunication occurring, it did not necessarily address some of the other non-language barriers. These barriers were seen to cut across all consultations irrespective of the patient's ability to speak English or whether or not they were accompanied by an interpreter. In Mr Raza's case, his personal and cultural 'beliefs' appeared to have been a barrier to him starting on insulin therapy yet, instead of discussing these issues with the nurse, he kept on asking for more time to prove to that he could control his blood glucose levels. Like other patients in this study, he may have wanted to present himself to his health professionals as a 'compliant' and abiding patient. There is also the issue of how he chose to present himself to me and the possibility that he wanted to come across as a 'good' Muslim

Both Mr Shabir's and Mr Raza's professional interpreters had previously interpreted for these patients but unlike lay interpreters who interpret for their family and friends they had relatively limited involvement with their clients outside the consultation. This situation stood in contrast to the case study involving Mrs Salma, who used a friend to interpret and, who regularly discussed her health concerns with her friend and sought her advice. I will now describe this case study involving Mrs Salma and her lay interpreter but later in the chapter, I will return to parts of the case study involving Mr Raza, and will draw upon my interviews with his interpreter and, his health professional, in order to explore and understand their experiences of taking part in triadic consultations.

## **8.5 Mrs Salma**

Mrs Salma, aged 41 years, was diagnosed with diabetes four years ago. She had migrated from Pakistan with her children to join her husband, and worked as a dressmaker at home. She told me that her spoken English was limited and that this was due to memory loss resulting from her diabetes. Again this comment could be interpreted as a face-saving exercise on her part, as she may not have wanted me to perceive her as 'incapable' of managing her consultations herself. She had been living in the UK for seven years and had recently begun insulin therapy. Mrs Salma yearned to return to Pakistan and talked about going over to arrange her daughter's marriage. She told me how her husband had recently suffered a heart attack and felt it was because he worked so hard in this country.

In her upcoming consultation she, like Mr Raza, was due to consult with a DSN and a dietician (these were not the same health professionals that Mr Raza had consulted with). Mrs Salma had been asked by her consultant to see the nurse as she was concerned that her blood glucose was high. An appointment with the dietitian had been requested by her friend when she had accompanied her to her previous consultation as she thought that it would be useful if Mrs Salma talked about her diet.

### **8.5.1 Pre-consultation interview**

Mrs Salma lived in a 3 bedroom flat and I arrived there shortly before 11am on the day of our interview. The bell to her home was not working so I ended up knocking on a window which I guessed was one belonging to her home. She peered out through net curtains and let me into the flat. She asked me to take my shoes off and follow her into one of the bedrooms. The room had a double bed in the corner and an electric heater was running. The rest of the room had a large table with a sewing machine on it and, there were different kinds of materials, threads and plastic bags filled with clothes strewn across the room and the bed. She made space for me to sit on the bed and sat next to me and began to unstitch a garment.

I began the interview and, at first, she seemed disinterested and asked me if I would finish interviewing her before noon, the time at which her husband came home. Mrs Salma told me that her GP had recently diagnosed her with hepatitis C and she was awaiting test results to establish what type of treatment she would be required to begin. In light of this, she appeared convinced that her upcoming diabetes consultation with the nurse was arranged so that this new diagnosis could be discussed with her:

*“I don’t know what will happen in this appointment because I have hepatitis C and I don’t know what will happen, like how many doctor’s there will be, what meetings they will hold, what they will or won’t do to me.”*

She was uncertain why this appointment had been requested and what to expect from the consultation. Any concern for her diabetes control appeared to have been over-shadowed by the threat Hepatitis C imposed upon her well-being and Mrs Salma seemed anxious about attending her upcoming consultation:

*“This worry has hit me hard. This is a new problem that has come my way now. I don’t know what will happen at my next appointment.”*

She seemed to engage with me more when we started talking about her Hepatitis C than when we talked about her diabetes and its management. She made me feel more welcome by offering me a drink and I began feeling less stressed about completing this interview before her husband came home. Mrs Salma was usually accompanied by her sister to her consultations but she had recently moved to London and so she had asked her friend to interpret for her instead. This friend was also a regular customer who paid Mrs Salma to sew traditional Pakistani outfits for her.

## **8.6 Mrs Salma's interpreter**

Mrs Salma's interpreter was a friend of my family and it was her who had put me in touch with Mrs Salma as a potential respondent for the study. She was in her late thirties, was born and raised in the UK and, had little experience of interpreting other than for Mrs Salma. She was not working but had done some translational transcribing work in the past as she was fluent in both English and Urdu/Punjabi. Compared to both the professional interpreters, her knowledge about diabetes was limited except for the information she had gathered from accompanying Mrs Salma to her consultations. Neither she nor any of her family members were known to have diabetes.

## **8.7 In the waiting room**

The interpreter and Mrs Salma travelled separately to the hospital on the day of the consultations. When I arrived at the hospital, Mrs Salma was already there but the interpreter arrived 15 minutes later than the appointment time. Whilst we waited for her, Mrs Salma told me that she had started taking homeopathic medication for her hepatitis and seemed convinced she would be cured in a matter of weeks. She asked me not to disclose this information to the health professionals along with the fact that she was working at home as a dress maker. The interpreter eventually arrived and we were immediately escorted by the DSN into the consulting room. This was a relatively large room with a plentiful supply of chairs. I was able to create a comfortable distance between the interacting triad and myself.

The nurse, who was in her forties, had consulted with Mrs Salma before. The consultation began with what seemed a fairly long prologue from the nurse during which she explained that Mrs Salma's notes had gone missing and what they were doing to locate them. This was not interpreted and the nurse then outlined what had occurred at Mrs Salma's last

consultation. Below is the end of the nurse's prologue just before the interpreter began to interpret:

Nurse: *"...when Mrs Salma saw Dr [name omitted] in November, her blood sugar control wasn't as good as what we would like it so she had asked her to come back and see me and the dietitian just to see who could find out what the problem is and just tighten things up a little bit."*

Interpreter: *"Right, she is saying that when you came here last November for an appointment..."*

Mrs Salma: *"Yes, yes."*

Interpreter: *"And then your blood sugar levels were a bit high and that is why they have called you in today again, to see the nurse and so the dietitian can talk about things about your diet and that's what they will do, they will do more check- ups."*

Unlike the nurse in Mr Raza's consultation, this nurse appeared to be talking to the interpreter rather than directly to Mrs Salma, hence she referred to her in the third person. In the above dialogue the interpreter told Mrs Salma that 'they' would be doing 'more check ups' when the nurse had not talked about conducting any tests. Also, the preamble about her missing notes was never interpreted. Since the nurse had spoken continuously for a considerable amount of time before allowing the interpreter to speak, it is unsurprising that the interpreter was struggling to keep up with the conversation. The following example is from a dialogue about Mrs Salma's blood glucose readings. She had been asked to fill out a diary with blood glucose readings taken several times during the day. However, Mrs Salma had only recorded her morning readings:

Nurse: *"Now it can sometimes be various reasons why somebody's control is not improved in the way we would like it, certainly the blood sugars you've recorded here [looking at diary] at breakfast times are perfect, they're exactly where we want them to be."*

Interpreter: *"she is saying that these readings are perfectly fine."*

Mrs Salma: *"yes the doctor also told me that, it was Dr [name of GP], he said that it should be up to 7 or within 7 before eating and then that is good."*

Interpreter (in English to nurse): *"she's aware that it's good."*

Here we can see how the interpreter synthesised what the nurse said into a short sentence, interpreting only the latter part of what she had said. Moreover, the interpreter did not interpret back what Mrs Salma said about the GP but offered her own view that Mrs Salma was 'aware' her blood glucose readings in the diary were 'good'. In different ways both the nurse and the interpreter sometimes inhibited full and accurate communication. The interpreter was seen to misinterpret and, the nurse did not help the situation by talking in long and complex sentences. It could also be argued that Mrs Salma was, in part, responsible for the kind of communication that was taking place. Arguably, she must have been aware that more was being said by the nurse than was interpreted, yet she did not challenge and question this.

Nevertheless, there were occasions when the dialogue between the three parties flowed coherently. The following excerpt is an example of such an observation:

Nurse: *"Right so it's only in the...could you tell me what results you get in the other times of the day?"*

Interpreter: *"She's asking how it is during the rest of the day?"*

Mrs Salma: *"it is fine"*

Interpreter: *"She says it is fine."*

Nurse: *"is it the same numbers as these [pointing at diary]"*

Interpreter: *"are the numbers same like this?"*

Mrs Salma: *"they are on average ok"*

Interpreter: *"they are overall fine"*

Here, it appeared the interpreter was able to interpret fairly accurately and there seemed to be two reasons for this. Firstly, the questions asked and the responses given by both the nurse and Mrs Salma were short which meant that the interpreter only had to process small amounts of information at any one time. Secondly, there was no technical language or medical jargon used, which could have made the interpretation process more complicated. By contrast, the following example illustrates what happened when much longer sentences were spoken together with technical terms being used. Here the nurse is attempting to explain the ways in which insulin worked:

Nurse: *"I mean the insulin that you're on it works at 30 percent quick acting and 70 percent long acting term, in the morning at breakfast time the*

*quick part works till lunchtime and the long part works till tea time and then you take your second insulin, the quick part works till bed and the long part works till breakfast, so do you want to [gestured with her hand to the interpreter as if indicating to her to start interpreting].”*

Interpreter (in Punjabi): *“she is saying about how insulin works.”*

Interpreter (to the nurse in English): *“30 percent?”*

The interpreter appeared baffled which was unsurprising as the nurse was asking her to interpret detailed and complex information. The nurse made the assumption that the interpreter could understand, remember and interpret all this information. She made no attempt to explain the terms ‘quick acting’ and the ‘long part’ which really needed to be understood by the interpreter for her to offer an accurate translation. The interpreter’s subsequent questions ‘forced’ the nurse to re-iterate the information but at a much slower pace and with many more pauses. This enabled the interpreter to translate smaller chunks of information. For instance:

Nurse: *“So there’s basically 4 points in a day which show us how well your blood sugars are being controlled, how well the insulin is working.”*

Interpreter (Punjabi): *“she is saying there are 4 points in a day which tells you how well your insulin is working.”*

Nurse: *“ok so at lunchtime any blood tests we do at lunch time tell us how well the quick part of the morning insulin works [the nurse stopped talking and looked over at Mrs Salma giving an indication that she wanted the interpreter to begin interpreting].”*

Interpreter [Punjabi]: *“the lunchtime...”*

Interpreter (to nurse in English): *“insulin isn’t it?”*

Nurse: *“yes insulin sorry blood tests.”*

However after a short while, the interpreter seemed to struggle again and had difficulty keeping up with what the nurse was saying. Unlike Mr Raza’s interpreter she was not able to control the pace of the conversation and was not picking up on the nurse’s cues to begin interpreting. This was partly because she struggled to understand what the nurse had said and although she did pose some questions to the nurse to seek clarification, she sometimes struggled on instead of admitting her lack of understanding. As long as the interpreter could



offer the nurse some kind of response she was keeping up with the order of ‘turn-taking’ characteristic of conversations and which enables the conversational exchange to progress.

During the consultation the nurse moved away from the interpreter and Mrs Salma to fetch a blood glucose monitoring kit from a cupboard. The interpreter began speaking to Mrs Salma in a hushed voice and asked her:

Interpreter: *“Are you taking the vitamins?”*

Mrs Salma: *“Yes I am taking them, I didn’t know why this was happening and to this extent.”*

Interpreter: *“Weakness does affect you somehow.”*

*[The nurse returned]*

Here we can see how the interpreter initiated a conversation between her and Mrs Salma which had no relevance to what the nurse had been discussing. She also offered her opinion when she said that ‘weakness affected’ her (Mrs Salma). This conversation arose because of their relationship outside of the consultation. This interpreter appeared to have a genuine concern for Mrs Salma’s health and not just about what was being discussed during the consultation.

## **8.8 Messages arising from the consultation**

The following example from this consultation illustrates how important it is to ensure that patients have accurately received and understood the main messages coming out of the consultation. Below, the nurse is again conveying some complex information and, more importantly, she is explaining what actions Mrs Salma needs to take in light of their discussions so far:

Nurse: *“So I suspect that if the insulin needs to go up it will be the morning one, don’t increase the evening insulin because that’s working nicely if you put your evening insulin up anymore you risk having a hypo though the night or first thing in the morning coz these morning readings are good which...”*

Interpreter: *“she is saying to put the morning insulin up as your evening insulin is going good”*

Mrs Salma: *“ok.”*

Nurse: *“so if they’re high during the day...morning insulin and the same as you’ve done before add in two units on every three days until the levels come down.”*

Interpreter (in Punjabi): *“if it’s high during the day, then increase the dose a little bit and then it will become better.”*

The nurse cautioned against increasing the night-time dose of insulin because of a potentially serious risk – a hypoglycaemic attack, however none of this was conveyed to Mrs Salma. My suspicion (which was later confirmed during my interview with the interpreter) was that the interpreter was unfamiliar with the term ‘hypo’ and what it meant, but instead of admitting this and asking the nurse to explain, she omitted some vital information. Moreover, the interpreter did not specify, as the nurse did, how much her dose would need to be increased. Indeed, when I questioned Mrs Salma, during my post-consultation interview with her and asked her about what she had understood as being the main messages arising out of the consultation, she said:

*“Yes she was telling me to adjust my insulin in the morning and not to do it too much during the night but it depends on how much my sugar is.”*

It seemed that Mrs Salma had not quite received the message which the nurse had intended to deliver. She thought that she could still increase the insulin at night but not ‘too much’ whereas the nurse had advised her to not increase it at all in case she suffered from a hypo. There was also the danger that Mrs Salma might adjust her day time insulin by too much or too little and which could be detrimental to her blood glucose control. The nurse had limited means of knowing what messages Mrs Salma did or did not receive, a point to which I return later in the chapter.

I will now briefly mention some of Mrs Salma’s after-thoughts about the interaction, particularly as her expectations differed from what had happened during the consultation. Mrs Salma was confused because, contrary to what she had expected, her hepatitis C had not been mentioned. I asked her why she thought this was the case and she said:

Mrs Salma: *“Maybe because it was the nurse’s appointment, I think I may have it but she didn’t bring it up.”*

NA: *“Did you feel that maybe she should have mentioned it?”*

Mrs Salma: *“No I have an appointment with the doctor.”*

In the pre-consultation interview with Mrs Salma, she had told me that she expected the issue of her hepatitis C to be discussed. However, this did not happen and, as the above quote suggests, she had made sense of why this may have been the case by commenting that it was not the nurse's responsibility to deal with it. When I enquired about this with the nurse, in her post-consultation interview, it actually turned out that she was unaware that Mrs Salma had recently been diagnosed with Hepatitis C and she said that she would have discussed it with her had she known.

Matters may well have been different if Mrs Salma had been able to converse directly with the nurse as she may have chosen to raise this issue herself. As it was, she made no attempt to mention her Hepatitis C through the interpreter suggesting that she may have been feeling less anxious about this worry as she perceived there to have been no fuss made about it. However, an alternative explanation is that the nurse created little opportunity for Mrs Salma to raise any issues or ask questions. At no point during the consultation did the nurse ask Mrs Salma if she had anything she wanted to ask. The consultation discussion consisted of mostly closed questions and providing Mrs Salma with information related to her insulin intake.

## **8.9 Post-consultation interview with Mrs Salma**

In my post-consultation interview with Mrs Salma, I asked her if she had been checking her blood glucose levels more than once a day as the nurse had suggested and, whether she had been adjusting her insulin accordingly. She told me how she only checked her blood glucose readings in the morning and took insulin on the basis of that reading. She also explained why she had asked me not to disclose to the health professionals that she was taking homeopathic medication. Seemingly, the last time she had tried using an alternative therapy for her diabetes control, she had discussed it with her GP who had discouraged her from pursuing this option. Hence she had decided not to share this information with health professionals anymore. The same friend had interpreted for her in her consultation with her GP and seems to have influenced her decision to keep this information to herself during consultations:

*“Yes she [GP] told me not to take the other medicines; you can ask [interpreter’s name] if you like, she told me not to tell the doctors so that is why I asked you not to mention this when we were at the hospital.”*

Mrs Salma’s friend seemed to encourage and support her decisions and choices even if it meant going against the doctor’s advice. Mrs Salma not only relied on her friend to communicate during consultations but sought her judgment and guidance on how she should use the information gained from her consultations. Unlike the professional interpreters described earlier, this interpreter appeared to lack diabetes knowledge and struggled to understand and interpret some of the information discussed in the consultation, yet, for Mrs Salma, she offered support which went beyond the consultation setting. This was something which the professional interpreters did not offer.

So far, I have described how interpreters may affect communication during the consultation interaction and also how ‘good’ interpretation may not necessarily promote effective communication. By ‘good’ interpretation I am reflecting on what I thought was compared to Mr Shabir’s interpreter’s style, consistent and accurate translations of what was said between some patients and their health professionals. Additionally, some of the health professionals own views on what constituted ‘good’ interpretation informed this judgement. Examples of this kind of interpretation were illustrated at several points in the previous case study involving Mr Raza. His interpreter was seen to, for the most part, accurately convey both the patients and health professionals ‘talk’. ‘Good’ interpretation also consisted of important non-verbal cues such as making and breaking eye contact and creating appropriate spaces and gaps during the conversation to allow for interpretation. Good interpretation was also seen to be encouraged by health professionals when an effort was made by them to speak in smaller and simpler sentences as was seen in the case study involving Mrs Salma on page 191.

So far, I have shown how a professional interpreter facilitated communication and how a lay interpreter made every effort to do the same but struggled to make sense of the consultation content. These triadic interactions were also in part dictated by the kinds of relationships interpreters and patients had outside the consultation setting. In the following section, I will present some of the views that Mr Raza, Mr Shabir and Mrs Salma held about their interpreters to further illustrate the effect of these relationships upon the consultation process.

## 8.10 Patient's views about their interpreters

Like other patients who had used professional and non-professional interpreters in this study, Mrs Salma held a 'positive' opinion of her interpreter. I asked her if she felt having an interpreter was helpful to her:

*"yes very useful, my sister used to go with me every time but now she is busy all the time and [interpreter's name] asked me many times if I ever needed her to interpret but usually it was my sister who would go with me."*

I asked Mr Raza what he looked for in an interpreter and he similarly commented:

*"An interpreter who can relay your information to the doctor properly and then relay the doctor's information properly back to me, I have been very lucky with all the interpreters who have accompanied me as they did exactly that."*

Similarly, Mr Shabir voiced positive comments about his consultation even though to me, it appeared to have been a 'difficult' one. Given that patients seemed unable to judge the quality of interpretation it would be difficult for them to offer any critical opinions of their interpreter. None of these patients raised the issue of why interpreters appeared to interpret more or less of what they were asked to interpret. Health professionals on the other hand did raise this concern as I will describe later in the chapter. Firstly, in the next section of the chapter I will describe some of the opinions and views held by interpreters in the triadic consultations featured in this chapter.

## 8.11 Interpreters' perceptions of their roles

The interpreter's who took part in this study including Mr Shabir's interpreter (as described in the previous chapter) held different ideas of what their roles involved and this was partly informed by what went on between them and their clients/friend outside the consultation setting. I will now illustrate some examples which show how interpreters felt they sometimes had to manage a dual role.

### 8.11.1 The 'involved' interpreter

I begin with Mrs Salma's interpreter who, during the consultation, appeared to struggle when interpreting some of the technical information that the nurse asked her to convey. I asked her:

NA: *“did you feel you understood everything the nurse was telling you?”*

Interpreter: *“Yes I don’t have much knowledge about diabetes, I mean with the nurse there were a couple of things because it’s all the numbers like you know whatever points and that’s why I took some leaflets after so to really know what I am talking about, do I understand what she’s asking coz sometimes it can be difficult for me to translate when I don’t even know what she’s on about.”*

The interpreter admitted that sometimes she had difficulty understanding what the nurse said and also said that she intended on learning some of the technical terms for future consultations. However, not ‘*having much knowledge*’ did not stop her from providing Mrs Salma with advice about managing her illness:

*“I think because of her lack of English she’s quite well behind in knowledge wise like em what to do and what to know...when she has a problem she gives me the first phone call and I think because of the language she knows she can speak freely and openly and I can as far as my knowledge I’ll help her and advise her like we can do this, see a doctor or whatever you know suitable.”*

The interpreter confirmed that she was the first port of call for advice for Mrs Salma as she could communicate with her in her first language. Consequently, the interpreter had become familiar with how Mrs Salma was coping with her illness and felt she was required to do more than just interpret during her consultations:

NA: *“so are you advocating for her as well, I noticed a couple of times you asked questions which Mrs Salma hadn’t asked, did you feel that it was necessary?”*

Interpreter: *“yes I do, sometimes em she (Mrs Salma) doesn’t want to ask and it sort of clicks in your head that you just I don’t know you sort of think maybe you’ve got the illness and what you would do and you would probably ask this sort of question or the next question relating to that and it just comes automatically.”*

This interpreter perceived her role to be broader than simply offering verbatim translations. She felt that Mrs Salma was sometimes not inclined ‘to ask’ relevant questions so would propose questions to health professionals on her behalf that she felt were relevant. Indeed, when examining the consultation transcript between Mrs Salma, the dietitian and the interpreter some of the dialogue can be seen to include questions and answers that Mrs Salma had not conveyed. For instance, in the following quote Mrs Salma described how she managed her diet when she felt her blood sugar levels lowering to below the normal range:

Mrs Salma: *“now I get up at that time and have a glass of milk”*

Interpreter: *“‘Now she knows how to eat better before she wasn’t aware”*

Dietitian: *“ok”*

Mrs Salma: *“Now I don’t feel that anymore.”*

Interpreter: *“yeah a few months back she was taking natural beans out of a tin and her sugar levels were up and she didn’t know what was causing it so she’s reduced that too to less sugar beans.”*

Here, we can see how the interpreter offered the dietitian information that Mrs Salma had not brought up. In her pre-consultation interview Mrs Salma had told me that the interpreter had advised her about making this change and how it had made a difference to her sugar levels. Similarly, in another part of the same consultation the interpreter asked for information which Mrs Salma had not mentioned:

Interpreter: *“yeah she still doesn’t know how to read labels and how to calculate how much sugar intake she needs to take or salt.”*

Dietitian: *“ok em I can get some written information about that from the website if possible, which language is it?”*

Interpreter: *“Urdu”*

I gathered from my interview with the interpreter that she had requested the appointment with the dietitian for Mrs Salma so that this information need could be addressed. As can be seen unlike Mr Raza’s interpreter she was much more than simply a ‘voice’ for Mrs Salma but also a form of support and someone who could guide her in getting information and advice. Irrespective of her limited diabetes knowledge, it appeared that she had Mrs Salma’s best interests at heart and genuinely wanted to help her friend which could be seen to extend into Mrs Salma’s consultation. Arguably, interpreting verbatim what the patients and providers say can be challenging for interpreters as it requires distance and impartiality at the risk of appearing uncaring. This can be more of a dilemma when someone is a friend/relative as well as the interpreter, because it may not be easy to set aside their relationship when interacting in these consultations. In the next section, I will illustrate that even professional interpreters who do not have such a close relationship with their clients can also face challenges and dilemmas

### 8.11.2 The ‘impartial’ interpreter

As illustrated earlier, Mr Raza’s interpreter translated verbatim both the health professionals’ and Mr Raza’s ‘talk’. I asked her questions about her role as she perceived it:

NA: *“How have you been trained professionally? How are you told to be during appointments?”*

Interpreter [in English]: *“you are always supposed to interpret what the official says and what the client says, you do not give your own opinions, everything has got to be above board. If someone asks you for your advice, you tell them I am not in a position to give you the advice. I am here to interpret for you.”*

The interpreter felt that the words of both parties should be accorded equal priority when being translated. It is worth pointing out that Mr Shabir’s interpreter, as seen in the previous chapter, also expressed similar views so there seemed to be a clear understanding amongst these professional interpreters of how they ‘should’ interpret. I asked Mr Raza’s interpreter:

NA: *“Do you feel that you are representing the patient or the health professional or both of them equally?”*

Interpreter: *“I think equally because it’s a team effort. I am there for both of them. If I was just there representing the patient then who would be there for the health official? I have to put their point across to the patient and likewise both ways. That is the way it works.”*

Indeed, this interpreter demonstrated what she advocated, and unlike both Mr Shabir’s and Mrs Salma’s interpreter, she appeared impartial throughout the consultation interaction except when she sometimes offered contextual information. She told me how she tried to maintain her impartiality outside as well as inside the consultation but this was not always easy and that sometimes she found herself in a position in which her ‘professionalism’ in terms of acting as a conduit risked being compromised. For instance she said:

*“With our people, especially with the aunties<sup>6</sup>, they say you are like my daughter, can you advise me what to do.’ Sometimes you are put in a very difficult position.”*

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<sup>6</sup> She referred to Pakistani woman similar to her own mother’s age as ‘aunties’. It is common practice amongst Pakistanis to refer to such people in this way.



When asked how she dealt with such situations her response was:

*“That’s a concern always and I have to tell them that I can only interpret and cannot give any advice...if it’s an aunty you know, somebody like my mum, I might say to them, I know of this group and my mum uses like ‘Milan’ who help the over 50’s...”*

She expressed concern that this kind of situation arose frequently and added that it may be a reflection that some patients were not receiving or understanding adequate information/advice during their consultations. She said that being able to provide advice would make her work as an interpreter easier in some respects as it was highly taxing having to justify her role and re-direct patients elsewhere:

Interpreter: *“If I had the expertise, it would make the situation a lot easier.”*

NA: *“why do you think it would make the situation a lot easier?”*

Interpreter: *“because sometimes you feel very rude.”*

NA: *“What do you mean?”*

Interpreter: *“if somebody is in distress and you know they are referring to you as a daughter or son and you turn around and say I can’t help you but so and so can. If you had the training you know to actually give people some kind of advice, be it housing, welfare or whatever you know...you can say something more specific to them, maybe point them in the right direction but right now we are not in the position to do that.”*

In trying her best to act in a professional way, Mr Raza’s interpreter described how some male patients made her feel awkward, embarrassed and sometimes angry. For instance, she described a consultation during which she was required to translate issues around erectile dysfunction with a Pakistani man. She explained that because she acted professionally with her clients she could deal with this discussion in an objective manner in the context of the consultation. However, problems arose outside the consultation when the same patient followed her as she made her way outside the hospital and insisted on discussing his sexual problems with her. She commented:

*“That it was the most awkward situation I have ever been in my life. If my husband ever found out he would put a stop to my interpreting.”*

In another incident she recounted how:

*“Once I was with a client who must’ve been about my dad’s age. He asked me as we came out of the surgery that I was a bit embarrassed to ask you then but I actually wanted Viagra. I wanted to turn around and say to him, I am the same person that I was in the surgery and I haven’t changed.”*

In general, she considered gender matching between the interpreter and the client an important factor to avoid such situations from arising.

Because this interpreter belonged to the Pakistani community, patients would sometimes want to know more about her and her background. However, she emphasised the importance of confidentiality which also applied to the way she acted towards her clients:

*“You know through our community you seem to find out who everybody is. Then again there is always that confidentiality thing, I never ask anybody about anybody, doesn’t matter if it’s a member of their family. I do not ask – how is...I know his daughter is having problems. I know his wife’s been ill but I’ve never asked Mr Raza how the rest of the family is because that’s not what I am there for. I am just there for him, whatever he needs me for, you know to interpret for.”*

In some ways, Mr Raza’s interpreter experienced the same dilemmas as did Mrs Salma’s but had developed a different set of strategies to deal with these. By making it clear that she was not prepared to participate in any conversations to do with other members of the community she ensured that she did not become involved with the client outside the consultation. This contrasts with the way Mr Shabir’s interpreter perceived and managed these dilemmas as I will now go on to show.

### **8.11.3 The interpreter who offered his guidance**

Like the other interpreters, Mr Shabir’s interpreter also had to juggle the demands arising from being an interpreter and a member of the Pakistani community. However, Mr Shabir’s interpreter did not emphasise confidentiality issues to the same extent as Mr Raza’s interpreter, and he claimed he would give his number to those clients who asked for it. He felt it was part of his ‘duty’ to help patients both inside and outside of the consultation:

*Mr Shabir’s interpreter: “After the appointment after we have left the consulting room, they will ask me for my phone number [laughs] because they want to ask me questions and so I give it.”*

He continued:

*“If we have information about certain things then it is our duty to provide that advice so we will provide that for example, like where they can get their medication from and how they are meant to pay the whole benefits thing. So whatever knowledge we have we will try our best to explain to them. But if we don’t know much about something like a medical thing and we don’t know about and can’t give advice so we don’t give any and leave it to the doctors and nurses.”*

This interpreter was willing to impart information that he felt he was able to provide. Although the main type of information requested from him were to do with practicalities, such as enquiring about a bus route to a hospital, rather than medical queries, he, unlike Mr Raza’s interpreter, felt it was his ‘duty to provide that advice.’ He also said that he would attend appointments in addition to the ones organised by the agency if patients requested that he accompany them:

*Interpreter: “Basically everything that I can tell them I will and that is why patients honour me so much and like me because I will go out of my way to help them and sometimes I will go along with them.”*

*NA: “Is that without being paid?”*

*Interpreter: “yes without pay. I feel it is my religious duty, if I have time I will go with them.”*

Both of the professional interpreters described their experiences in relation to their perceptions about their community and how they reacted to it. Mr Raza’s interpreter felt her role would be made easier if she was able to provide more support in terms of information provision to her clients but was bound by the remit of her role as an interpreter and her ‘limited’ knowledge. On the other hand, Mr Shabir’s interpreter seemed to be using his interpreter role to build up his standing or ‘honour’ in the community by making himself accessible to his clients.

Thus far I have illustrated and discussed some of the experiences and views of the interpreters who took part in this study. Interpreters were frank in their opinions of interpreting for patients and when asked about their perceptions of how the health professionals handled these consultations their comments were largely positive:

*Mr Raza’s interpreter: “I think from my point of view they are doing very well.”*

Mrs Salma's interpreter: *"yeah she [the nurse] was fine. She explained everything clearly."*

Although, the health professionals were sometimes observed to have spoken in long and complex sentences making it difficult for them to translate, this did not affect their positive perceptions of healthcare professionals. Nearly all the health professionals, who took part in this study, on the other hand, had plenty to say about the interpreters they encountered, as I now go on to describe.

## **8.12 Health professionals' perceptions of Mr Raza's interpreter**

Mr Raza's nurse had booked a double appointment to take into account the three-way communication. Her view on the interpreter was:

*"I thought the interpreter was excellent. She was very good and, you know, she...she obviously had some knowledge of diabetes as well, so I thought she was good and I think he felt...you know...he [Mr Raza] was smiling back and, you know, at jokes and various things like that, so I think we had quite a good conversation that way."*

By the way Mr Raza reacted, the nurse could tell that even her jokes were getting translated which, in her mind, contributed towards developing a 'good conversation' and a good rapport. The interpreter was seen to have 'some knowledge of diabetes' which the nurse welcomed suggesting that health professionals may expect more than just verbatim translation. The other aspect the nurse commented upon was the time the interpreter took to convey the translated information in either direction:

*"..and from what I'd said, the time that she took to tell him tallied because sometimes you'll get an interpreter that they say far more than what you've actually said or you're sure that they are adding in their own bits, you know."*

If the interpreter spent roughly equal amounts of time between listening and translating information then this was taken as a good indicator that interpretation was fairly accurate. The dietitian was similarly impressed by the way this interpreter conducted her role and further added:

*"I mean, the girl who was translating was excellent I thought and its really good when you get some feedback from her or, you know, the fact that she clarified a couple of points before she spoke to him...the questions she was*

*asking were highly relevant. That showed she had a sort of deepened understanding..."*

That the interpreter sometimes questioned and 'clarified' information with the health professional before translating it back to Mr Raza seemed to impress the dietitian and convinced her that she was interpreting well. Having no concrete way of establishing the quality of interpretation this clue seemed valuable in assessing the interpreter's performance. It is worth noting at this point that patients did not appear to assess the interpreter's performance in the same way as the health professionals in this study did. Patients tended to comment upon interpreters' performance during the consultation. One explanation might be that patients used criteria different to that used by health professionals to assess how well their interpreter did their job. As discussed in a previous section of this chapter, patients expected more from their interpreters than just to interpret for them. Whereas health professionals based their assessments on the interpreter's performance during the consultation interaction, patients', largely positive, opinions may be informed by what goes on between them outside the consultation.

### **8.13 Health professionals' perceptions of Mrs Salma's interpreter**

The nurse in Mrs Salma's consultation was not as certain as Mr Raza's health professionals had been about the quality of interpretation:

NA: *"Do you think the interpreter found it ok to interpret?"*

Nurse: *"I think it can be quite difficult as well depending on the interpreter's knowledge of diabetes as well em and I feel at times I would give sort of small bits of information and wait for her to put it back and she didn't always seem to take me up on that."*

She felt that the interpreter did not always take her up on her cue to begin interpreting back to Mrs Salma even when she provided her with 'small bits of information'. This was an interesting perception as I had observed how the interpreter had managed information better when it was delivered in smaller blocks by the nurse. She seemed to question the interpreter's diabetes knowledge and sometimes got the impression that perhaps she did not understand everything that was being said to her. Although it appeared that both Mr Raza's and Mrs Salma's health professionals did not necessarily expect the interpreters to have diabetes knowledge, they found this aspect to be useful when dealing with them.

The nurse ‘hoped’ that Mrs Salma had received the intended information but there appeared to have been no way to confirm that she had:

Nurse: *“I suppose when you have the interpreter there it goes a little slower obviously because of that so you’re maybe not getting as much information across.”*

This nurse felt that the time it took to speak through an interpreter could be a barrier to getting ‘as much information across’ because things were ‘slower’ compared with speaking directly to a patient. Mrs Salma’s dietitian made a general observation about interpreters and expressed how sometimes conversations between interpreters and patients left her feeling uncertain about what was being said between the interpreter and the patient:

*“that that is one of the things I felt and it varies with what interpreter you get but sometimes it feels that there is a lot of conversation goes on between the patient and the interpreter and not very much comes back to us em it can be difficult to know whether the patient’s gone around the houses to say something very simple or we’re not actually getting all the information back.”*

This sentiment was strongly echoed by nearly all the health professionals that were interviewed as part of this study such as by this male doctor:

Doctor: *‘I think communicating through a third party is very, very difficult cos you get these conversations where you ask a question and then there’s a big long dialogue between the two people and then they come back and say yes or no ... (LAUGHS) ... and you feel you’ve missed out on an awful lot of that dialogue which could have been helpful’.*

It seemed that relatively ‘long’ conversations between patients and interpreters during the interaction sometimes brewed feelings of uncertainty and ‘concern’ amongst health professionals as they gained the impression that more than interpretation was going on.

Mr Ibrar’s doctor: *‘I think interpretation...makes it harder to build a rapport because almost...their interpreters building a rapport by sort of saying a nice thing to sort of welcome them in and it makes it harder to share a joke, it makes it harder to empathise, I think through an interpreter. Cos if someone said to his interpreter, oh my mother died last week...the interpreters saying, oh I’m terribly sorry, I think it kind of loses some of the meaning.’*

Mrs Nargis GP: *‘I mean, any interpreter’s better than none cos you do often get consultations where there’s nobody there and you really are not*

*sure how much has been understood. That ... that can be difficult, em ... but, no, I mean, I work with whoever comes and try and make sure that the ... the information is getting across as ... as clearly as possible.'*

Most of the health professionals who took part in this study expressed a preference for communicating through a professional rather than a lay interpreter:

*Mr Shabir's Doctor: 'Well, I think the ones when you've got a professional interpreter are better than the ones when you've got a relative because the relative tends to either answer for the person ... (LAUGHS) ... or kind of just gives selective information I think, whereas the interpreter tends to just give the whole thing'.*

However one dietitian recognised that lay interpreters may offer some information that may be useful to the consultation:

*Mr Raza's Dietitian: 'On other occasions, of course, insider knowledge of the family is of inestimable ... so that when grandma or grandpa or mum and dad is sitting there saying, no I would never eat that anyway, they're sitting saying, yes you do ... (LAUGHS) ... so it can work both ways I think for you. But perhaps particularly for some people, it's probably better to have somebody you don't know ... a professional translator.'*

## **8.14 Summary**

In this chapter, I have shown two case studies, one involving a professional interpreter and another involving a lay one. The translating style of Mr Raza's professional interpreter when compared with Mr Shabir's interpreter was markedly different, in that, she translated most of what was said verbatim. She ensured that she translated accurately, partly, by creating spaces and gaps in the conversation and by making good eye contact with both Mr Raza and the nurse. Although, no miscommunication and misinterpretation occurred in this consultation this did not necessarily promote effective communication as Mr Raza was in disagreement about the treatment decision that was being made amongst other things, yet he did not voice this during the consultation. Mrs Salma's lay interpreter was seen to struggle to understand what the nurse had asked her to translate, partly because of the long and complex sentences spoken by the nurse, but also because this interpreter lacked knowledge about diabetes. This resulted in a misinterpretation in which important treatment information was misconveyed to Mrs Salma and, which could potentially have caused serious problems in the management of her diabetes. Interpreters' perceptions' of their own roles inside and outside the consultation setting varied and this had implications for how they chose to

interpret. Mr Raza's interpreter felt that impartiality was important and thus translated in an 'objective' and accurate manner. Mr Shabir's interpreter said it was important, as a member of the community who he interpreted for, to offer them guidance and advice whenever possible and, this role was seen to extend into the consultation setting. Finally, Mrs Salma's interpreter who was also her friend during the consultation advocated and asked for advice on behalf of Mrs Salma. Health professionals seemed to have presented different complexities and dilemmas from the interpreters that I have talked about in this chapter. These included: their concerns about all of the information being conveyed between them and their patients; hindrances to rapport-building caused by communicating through a third party; uncertainty about how much diabetes knowledge interpreters had and, the time it took to translate as it slowed things down and there may be a risk that less information being conveyed. The professional interpreters appeared to be talking much more about potential role conflicts between being an interpreter and a community member with attendant obligations to others. Health professional's comments were focused upon the interaction itself and with the quality of interpretation. They had mixed views and felt that interpreting styles varied substantively between professional and lay interpreters.

In the following chapter, I will summarise and discuss the key findings arising from all four analysis chapters and also bring in some data from the case studies that I did not describe in the previous chapters.



## **CHAPTER NINE: FROM CASE STUDIES TO CROSS-CUTTING THEMES**

### **9.1 Introduction**

In this penultimate chapter, I will summarise the key findings that arose from the six case studies described in the four findings chapters which are most salient to the aims of this thesis. In doing this, I will also draw upon findings from the four case studies that have not yet been described to illustrate and reinforce the ways in which key findings reported in this thesis cut across the dataset. Whereas in previous chapters I presented whole case studies in order to illustrate my findings and analyses, below I will summarise and synthesise the key cross-cutting themes, drawing primarily upon data from the four case studies involving Mrs Amna, Mr Mirza, Mr Javaid and Mrs Naseem, and linking these data to data already reported in previous chapters.

### **9.2 Summary of key findings**

#### **9.2.1 Language Barrier**

In the case study involving Mr Khan described in Chapter Four, I illustrated how language was a serious barrier to communication which sometimes resulted in miscommunication and, on several occasions, caused breakdowns in the conversations between him and his consultant. I showed how Mr Khan struggled to express himself and how the consultant found it difficult to obtain answers to several of his questions. This case study served as a useful starting point for my analysis and presentation of findings as it not only illustrated how a language barrier can undermine communication between a patient and their provider, but it also set the scene for the exploration of other themes that began to emerge in this example. These themes included assumptions about Pakistani patients held by some providers and how patients would keep their consultations simple and thus easy to manage.

In the following chapter I introduced Mr Ibrar who spoke better, albeit still limited, English than Mr Khan. This example enabled me to explore whether Mr Ibrar's slightly better English language skills resulted in better quality of communication between him and his doctor. In this case study, I did find that there was less miscommunication between Mr Ibrar and the consultant. However, while Mr Ibrar's 'better' English made the conversation

between him and his doctor easier than was observed in Mr Khan's consultation, Mr Ibrar did not appear to gain much more from his consultation than Mr Khan did. In fact, both of these patients came away from the consultation with the same information and outcomes: the results of their blood tests and advice based on a review of their medication. Since these consultations appeared to be fairly straightforward and consistent in terms of the kind of information exchanged, both patients and health professionals did not consider language to be a barrier.

I observed how patients sometimes managed an English barrier by picking up on the familiar terms/words they had become accustomed to hearing during past consultation experiences. This strategy enabled them to understand the main messages arising from their consultation and kept the interaction straightforward.

### **9.2.2 Limited and narrow communication**

Mrs Nargis, on the other hand, did not need any such strategy as she spoke good English. I chose to bring this case study into my analysis at this point in the thesis to see whether her ability to speak good English enhanced communication in the consultation compared with those involving Mr Khan and Mr Ibrar. Although there appeared to be no obvious miscommunication, Mrs Nargis's communication with her GP was still limited, consisting of simple and short exchanges and she too came away with the same messages as did Mr Khan and Mr Ibrar. She, too, was informed her blood test results were 'ok' and was advised to continue taking her medication the way she had been doing so far. Very similar findings arose in the case study involving Mrs Amna, an educated woman in her fifties, who migrated from Pakistan around 20 years ago and spoke fairly good English. Despite this, and like Mrs Nargis, her consultation interaction with her hospital doctor also consisted of short exchanges which centred upon establishing how she managed to adjust her insulin dose to ensure her blood sugar was controlled. Sometimes the doctor asked Mrs Amna complex and technical questions which she appeared to answer without much difficulty yet the absence of a language barrier did not facilitate discussion that went beyond the focus upon her blood sugar levels and her treatment/medication.

Regardless of whether patients spoke good English or not, or were accompanied by an interpreter, these same two messages arose repeatedly in all the case studies. Given that many of these patients were attending diabetes-related consultations, it is not surprising that discussion of blood test results and medication formed an important part of these

appointments. However, what I began to discover was that the focus upon the same two messages served to limit these consultations and other important and relevant issues sometimes remained undisclosed as a consequence and, which could lead to inappropriate treatment recommendations.

### **9.2.3 Patients' undisclosed health concerns**

As I argued in Chapter Five, the messages that these patients took away from their consultations generally coincided with their limited diabetes-related pre-consultation expectations which were to have their bloods tested and medication reviewed. However, by virtue of my pre-consultation interviews with patients, I was privy to health concerns and management problems that many of these patients chose to share with me but did not always go on to disclose in their consultations. Mr Khan, for instance, had desperately wanted his heart problem addressed, but had struggled to raise this concern during the consultation, partly because of a language barrier. Had I just considered this case study in isolation, I would probably have seen a language barrier per se as being responsible for this non-disclosure but, by situating his case study alongside others, it became evident that there were also some other issues and reasons for non-disclosures of this type. Most of the other patients, who were potentially in a better position to raise issues than Mr Khan, in that they spoke more English than he did or were accompanied by an interpreter, nonetheless did not always disclose their diabetes-related concerns. Examples of this include Mr Ibrar who did not tell the doctor he experienced hypoglycaemic attacks and was unable to exercise because of his perception that it was more appropriate to discuss these issues with his GP with whom he had a long-standing relationship. Mrs Nargis also spoke highly of her long-term relationship with her GP with whom she said she could comfortably raise issues. However, she refrained from telling him that she was finding it difficult to undertake blood glucose self-monitoring in line with the requirements of being on insulin therapy because she disliked pricking herself several times a day. Mr Shabir suffered from the symptoms of his poorly controlled diabetes and had limited expectations of these problems being resolved. He held out little hope that his symptoms, such as diarrhoea and the pain in his hands, would ever be addressed in light of previous consultation experiences so appeared to have given up asking for help. Mrs Salma was taking homeopathic medication and, did not want her provider to know because previously, her GP had tried to discourage her from continuing with this therapy. A pertinent illustration is also provided by a British-born participant who took part in this study, Mr Mirza, a wealthy business man who was in his 50s and was being insulin-treated. However, like Mrs Nargis, he refrained from disclosing to his doctor that he

was monitoring his blood glucose much less frequently than he was advised to do so. During the consultation with his doctor at the hospital Mr Mirza was asked whether he monitored his blood sugar before he drove to ensure that he was not at risk of a hypoglycaemic attack and he had told his doctor that he did. However he told me in his post-consultation interview with me that he thought this was an unreasonable request because, as a car selling businessman, he was frequently required to drive and hence was unable to always monitor prior to driving. In addition to this practical difficulty, he also revealed to me, that he had had other concerns about monitoring, which he did not share with the doctor.

Mr Mirza: *“Another reason is that I don’t like needles. In order to check your blood sugar level I need to use a needle. The other reason is that by frequently using needles on the fingers the skin becomes hard. You lose the feeling in your fingers, actually I tend to drop things.”*

NA: *“Why haven’t you mentioned it to your doctor?”*

Mr Mirza: *“I am assuming that they already know. I do use pen and computer all the time so I do need the touch.”*

It could be argued that by virtue of being born and raised in Britain, Mr Mirza’s consultation with the doctor might potentially have had fewer barriers than the consultations involving patients who have migrated from Pakistan. However, this particular example reinforces the point that some barriers may exist irrespective of language since, like some of the other patients in this study, Mr Mirza did not use his consultation as an opportunity to explore and resolve problematic aspects of his diabetes self-management.

#### **9.2.4 Passive patients**

Another common theme running through all the analysis chapters was patients’ tendency to adopt what appeared to be a passive and submissive role in their consultations, irrespective of their language skills. For example as described in Chapter Five, Mrs Nargis appeared to take little initiative and asked very few questions. Similarly, Mr Ibrar appeared to agree with everything that his doctor said and did not play a very active part in the discussion. I have also illustrated in Chapter Two how Mrs Nargis’ and Mr Ibrar’s health professionals preferred their patients to be more challenging towards them and to not too readily agree with everything they said as their ‘resistance’ indicated to them that the patient was understanding what was being discussed. Unlike some of the other patients in this study, Mr

Javaid (60s), a retired wealthy proprietor, who had migrated from Pakistan in the early 1960s, was seen by his consultant to have played an active role in his consultation:

Mr Javaid's doctor: *"He seemed quite happy, I thought, yeah. And also he actually seemed to have a list of questions that he wanted to know, you know, which is quite unusual actually. So, you know, for example, he said, what is my sugar and ... you know, he wanted to know what his cholesterol was and things so, you know, he was making the effort to ask me things."*

This doctor thought that Mr Javaid was 'quite unusual' because he was proactive in asking her questions. Although some of these questions about sugar and cholesterol levels were also asked by other respondents, such as Mrs Nargis, and answers to similar questions were 'negotiated' by Mr Ibrar and Mr Khan, for Mr Javaid's doctor the fact that he asked questions had a positive bearing upon how she perceived him. Even though Mr Javaid's English appeared less fluent than Mrs Nargis' and Mr Ibrar's, his doctor appeared to be the most pleased with the way her consultation went with him simply because he came to the consultation with a list of written (in Urdu) questions.

### **9.2.5 what constitutes as successful communication?**

These findings raise important questions about what 'communication' meant in the context of these cross-cultural consultations and what patients and health professionals perceived as examples of good communication. Irrespective of a patient's ability to communicate in English, or through an interpreter, I could see how these consultations were restricted or narrowed when issues relevant to the consultation were not raised by the patient or indeed solicited by their healthcare professionals. In other words, effective communication was not simply about addressing the language barrier and removing miscommunication but also about sharing information that may have been relevant and could have changed the course of the consultation. Most health professionals generally critiqued the quality of the consultation on the basis of their staccato communication with patients; on the other hand, nearly all the patients who took part in this study saw their consultation as being successful. What patients saw as making these consultations successful were the outcomes e.g. being given a prescription and/or blood test results rather than the processes which took place during the consultations. All of the patients said that they thought their consultation had gone well. Mr Khan described his consultation as "very good" even though, during it, he pleaded for interpreting support from me. Mr Ibrar described his doctor as being "unusually good" even though, by his own account, an inappropriate decision may have been made about his

medication on the basis of the information he chose to provide. Similarly, Mrs Nargis praised her doctor even though she barely discussed anything with him. Mr Shabir who I witnessed to have become increasingly disempowered during his consultation, also described it as having been “very successful”. Mr Javaid (see previous page), was in fact the only patient in my study to convey a more reticent view in his post consultation interview. In the first instance, he pointed to the limited expectations he had had of his consultant:

*“she was fine and what else she was going to do with me, she asked me questions and I would answer her, that’s all they do there it’s not as if they do anything else there.”*

Subsequent to this he reflected on why he and his fellow community members may be reticent about offering negative opinions about the health services they received:

*“The medical profession here can make mistakes too but we are not willing to speak up because we are just grateful that we are getting free treatment, if it was any British person to be mistreated they would be the first to speak up.”*

It appeared, then, that Mr Javaid was not entirely pleased with the services he received but stopped short from offering outright criticisms. It was important for him to express his gratitude for this ‘free’ service and it seemed that this ‘gratefulness’ and perhaps a desire to ‘speak up’ about ‘mistreatment’ could not coincide in the same account. It could be that the aforementioned patients who perceived their consultations to have been successful, were also toiling with this dilemma, and chose not to say anything negative at the risk of appearing ungrateful.

Arguably, patients may also have described these consultations as having been ‘successful’ because they followed a routine that they had come to take for granted and because they served a function which they had also come to expect. For example, Mrs Nargis expected to obtain her blood test results and a prescription and so, in her mind, the consultation had served its purpose. Similarly Mr Shabir, who came away with major unresolved issues, based the success of his consultation upon it fulfilling these same two routine functions. Mr Ibrar said his consultation was successful because it had helped to keep a ‘check on his sugar levels’. Even Mr Khan appeared to separate out these two consultation functions amidst all of the difficulties and miscommunication that occurred in his case. In one sense, then, as long as patients had enough English that permitted them to receive this information, it

seemed that they did not perceive there to have been a language, or other barriers, even when I witnessed one.

### **9.2.6 Interpreter Involvement**

If communication in these cross-cultural diabetes consultations was limited regardless of a patient's ability to speak and understand English then, arguably, an interpreter could do very little to enhance 'communication'. To this end, I explored and addressed this issue in my last two findings chapters, using three case studies involving interpreters. Sometimes, interpreters were found to introduce another set of issues and dilemmas into these consultations and in fact further complicated these consultations.

Mr Shabir attended with a professional interpreter and, although he did not raise all of his concerns, the ones he did mention were not always conveyed to his doctor by the interpreter. Mr Raza's interpreter did translate verbatim most of what he said but this did not necessarily encourage Mr Raza to divulge why he was so reluctant to start insulin, which was partly due to his personal understandings. He thought that his poor diabetes control was only a temporary state and was worried that, if he moved onto insulin this medication would make him 'weak'. The notion of 'weakness' in relation to medical treatment is a culturally-informed understanding which is, that ingesting too much medicine makes a person weaker and susceptible to illnesses. Finally, Mrs Salma's lay interpreter colluded with her to conceal from her provider that she was taking homeopathic medication because she had accompanied Mrs Salma to see the GP who, in the past, had discouraged her from taking alternative medicines. Given that these patients had interpreting support which is often cited as a benefit and which aids communication (MacFarlane et al. 2009; Bischoff et al. 2003; Hornberger et al. 1996) all these patients came away with the same two messages as those patients who attended without interpreters.

As described in Chapter Seven, interpreters talked about how they were often approached by patients outside of their consultations. These patients were looking for health-related advice and information and would sometimes even raise concerns with them that they did not during their consultations. One interpreter argued that this was because of a deficit in service provision in that sufficient information was not being provided to these patients and that, instead of turning to their providers for help, they asked their interpreters for it. The patient-interpreter relationship outside the consultation raised another set of challenges and dilemmas. For example, Mr Raza's interpreter described how she found it 'tricky' to simply

walk away from patients who were pleading for her help outside the consultation. Mr Shabir's interpreter felt it was his 'duty' and responsibility as a member of the Pakistani community to help patients both, 'manage' their interactions with their providers, and offer them further assistance outside the consultation. As I showed in chapter seven, Mrs Salma's friend/interpreter was her first port of call when she needed advice on health-related matters. This dependency meant that her friend sometimes made decisions for her both inside and outside the consultation.

### **9.2.7 Providers' views about their patients**

As previous findings chapters also served to highlight, the providers who took part in this study did not always see their consultations as 'successful' but interestingly they did not necessarily assign any shortcomings to a language barrier even when one was evident to me – in part, as I have argued previously, because patients had developed strategies to 'mask' their poor English and thereby 'save face'. As I described in Chapter Four, for instance, whilst Mr Khan's doctor acknowledged that there was a language barrier he also drew on other reasons and sometimes stereotypical assumptions to explain why his consultation with Mr Khan had been a 'disaster' from his perspective. Mr Ibrar's doctor considered Mr Ibrar's English to be adequate for the purposes of his consultation but complained that he was too passive which made it difficult for him to establish a rapport with him. He further assumed that his passive attitude was due to a cultural difference rather than because of language difficulties. Similarly, as described in Chapter Five, Mrs Nargis's GP recognised that she could speak good English but was frustrated that, despite their long-standing relationship, she agreed with everything he said, making it difficult for him to establish how much she had actually understood. This GP assumed that Mrs Nargis may have acted in this way because of her 'religious' beliefs that Muslim women should not openly talk with men who are unrelated or strangers. Mrs Naseem who was in her 50s and had migrated from Nairobi in her early 20s consulted with a doctor who similarly implicated cultural and religious issues to account for the difficulties he experienced when consulting with South Asian patients:

*Mrs Naseem's doctor: "It's more ... more, em ... communication. I don't feel that I'm, eh ... able to communicate as well and I think they have different issues, different understandings of issues than I do. Sort of their ... their understanding of health is slightly different, em ... and what's for them is for them sort of thing. I think some ... sometimes, you know, they feel that it's more fate ... you know, some of them do I think that ... that ... that, you know, that you're maybe not gonna influence your future as well as maybe white Caucasians might feel that they could."*



In saying this, the doctor inferred that the current advice offered in consultations, which emphasises patients' responsibility for their disease management, may not be suited to Pakistani patients, especially if they have a fatalistic attitude towards their disease and illness experience. Here, the doctor recognises that a clash in patients' and health professionals' viewpoints may be a barrier to be 'able to communicate as well'.

The above findings may have implications for the improvement of these consultations, especially since most of the emphasis in current recommendations is upon addressing the language barrier through the provision of professional interpreters, when, as I have shown, some health professionals felt that cultural differences are the major barrier to effective communication. If health professionals are highlighting barriers other than language then this suggests that we cannot keep focussing on overcoming single barriers, and that other problems need to be taken into account to help improve communication (This will be further discussed in the final chapter).

### **9.2.8 Providers' approach in the consultation**

Providers' consulting styles in the consultations I observed, also played a part in limiting 'communication'. At one extreme, Mrs Nargis' GP presented his patient with a series of closed answer questions to which understandably Mrs Nargis provided simple monosyllabic answers. Mr Ibrar's doctor attempted to adopt a patient-centred approach by asking him open-ended questions and inviting him to raise his concerns, but had to change his style to a more directive approach when Mr Ibrar appeared to struggle with providing answers to his initial questions. As I also observed in Chapter Seven, some of the providers used complex language and technical terms when either speaking directly to the patient or communicating through an interpreter. Both Mrs Salma's and Mr Shabir's providers made eye contact with the interpreters instead of with their patients which further restricted communication with them. Health professionals' seating position could also be seen to have a bearing upon the communication process, for instance Mrs Nargis's GP sat facing his computer most of the time whereas Mr Ibrar's doctor turned away from his computer and faced his patient suggesting a willingness to listen.

Finally by combining a range of methods, participants and perspectives, a greater understanding of the communication processes in these consultations was achieved than would have been achieved using any one method alone. The mechanisms through which this greater understanding was developed, has namely been through discussion of convergent,

discordant and unique findings. In the following chapter, I will explore and unpack these key findings in the context of the existing literature. The findings from this study will also be used to critically appraise this literature and to show how this study has added some useful insight to what is already known about the patient-provider interaction.

## CHAPTER TEN: DISCUSSION

### 10.1 Introduction

This final chapter comprises four sections. I begin by discussing how the findings summarised in the previous chapter can be interpreted in light of the existing literature and current theoretical insights into cross-cultural consultations. Secondly, I describe some of the methodological strengths and limitations of this study. I then use the findings from this study to provide some policy and practice recommendations for improving the quality of diabetes consultations involving Pakistani, and possibly other ethnic minority, patients. Finally, I provide some recommendations for further research.

### 10.2 Is 'effective' communication happening?

A key question raised from this research is what does effective communication mean? Charles et al. (1997) argue that communication in the context of shared-decision making, often advocated as the ideal model for treatment decision making in the medical encounter, is rather poorly and loosely defined. The authors attempt to provide conceptual clarity by defining effective communication, which partly involves a two-way exchange of medical and personal information between patients and their providers. This kind of communication is only possible when patients are encouraged to become involved as active participants in setting goals and agreeing on treatment plans. The provider's role is to respect patients' opinions and offer their support so that patients are empowered to take on a more active role (Charles et al. 1999). Consequently, effective communication enables the optimal use of these interactions as it encourages patients to engage with the advice/information provided to them during their consultations and apply it within their everyday lives (Charles et al. 1999; see also Neal et al. 2006).

If this definition of effective communication is used as the benchmark then it is clear that this level of communication was not occurring in the consultations observed in this study. Patients displayed little active engagement in their consultations and, for the most part, appeared to be passive and unquestioning recipients of information/advice and treatment decisions. Most of the time providers were seen to adopt an authoritarian role and, in most cases, there was little discussion around treatment decisions; rather, patients were simply *told* what to do. The focus of these consultations was not upon diabetes education provision

or discussing patient concerns and problems as such but, rather, upon blood test results and a review of medication. Past research studies have provided evidence that diabetes knowledge levels are poor amongst South Asians with T2DM (Ford et al. 2000; Simmons et al. 1991) and part of the reason given for this is that these patients may not be receiving adequate information and support during their consultations (Gerrish, 2001; Hawthorne, 1990). To this end, the observations developed as part of this thesis help to enhance understandings of why this may be the case.

While the literature has tended to implicate a language barrier (Gerrish, 2001; Schouten and Meeuwesen, 2006) and/or a cultural barrier(s) (Lawton et al. 2006a ; Hawthorne, 1990) to explain why consultations with South Asian patients may be problematic, the findings from my study suggest that these reasons may be too simplistic. A language barrier, in the context of the medical interaction, suggests that healthcare professionals are providing the appropriate information and advice but the patients are unable to understand this advice. Similarly, a cultural barrier suggests that the right information is being delivered, but in a culturally insensitive way. Thus, by addressing these barriers through the provision of, professional interpreters (Gerrish, 2001; Brooks et al. 2000) and/or, culturally-sensitive information (Lawton et al. 2006a&b; Hawthorne, 1990) it is suggested that the interaction could be made more effective. However, what this thesis has served to highlight is that the reasons why these consultations may be problematic is because barriers may be much more complex and/or subtle and inter-twined with each other. Recommendations that focus on addressing one barrier in isolation may risk over-looking other equally important barriers. I will now discuss the limited number of studies that have explored the interplay of a language difference in cross-cultural consultations and what further or different understandings the findings from my study may add.

### **10.3 A language barrier – is it an over-problematised issue?**

Despite there being a paucity of research examining how the quality of communication between healthcare professionals and patients with different English abilities varies, there is a widespread assumption and view that a language difference may cause major misunderstandings and miscommunication (Gerrish, 2001; Cooper-Patrick et al. 1999; Jacobs et al. 2006). The few studies that have attempted to explore the impact of a language barrier provide only limited reasons for these problems and tend to focus their discussions upon ways in which this barrier can be addressed. Frequently researchers focus their attention upon the problems associated with the availability and provision of interpreters.

The underlying assumption being made is that patients either can or cannot speak English so they need an interpreter, link worker or advocate, or they do not. For example, Gerrish (2001) examined the nature and effect of communication difficulties arising during interactions between nurses and South Asian patients in England. Nurse-patient interactions were observed involving patients who spoke little or no English and these observations were supplemented with interviews undertaken with the nurses. The author concluded that a language difference often caused patients to misunderstand medication instructions and based her conclusion upon the accounts provided by the nurses who reported that it was common for patients to not complete the course of prescribed antibiotics or take analgesics as instructed by their providers. However, reasons other than a language barrier may have come to light had the author explored patients' reasons for not adhering to medical instructions. The point to be made here is that it is often too easy to focus on a language barrier and this may come at the risk of overseeing other important barriers. Instead of just being concerned with 'treating the language barrier' by, for instance, providing recommendations on how interpreter services may be better co-ordinated (Gerrish, 2001), language needs to be considered one component part of the medical interaction.

In a similar vein, Ferguson and Candib (2002) conducted a review of those studies that have claimed to have examined the interplay of language in health consultations through either survey questionnaires or observations. The authors concluded that patients who are not proficient in English are less likely to engender 'affective' (empathic) responses (see Chapter Two) from their providers yet they do not provide any reasons for these observations. Instead, like Gerrish (2001), they focus their attention upon providing recommendations for how to manage language discordant consultations. In the current study, it was also found that healthcare professionals offered very few affective responses to their patients however, unlike Ferguson et al. (2002), they did not assign this lack of affect to a language difference; rather they referred to a cultural difference to explain why it was difficult for them to establish a rapport with their patients. I will elaborate on this point later in the chapter. The display of affective communication did not appear to be evident in the case studies illustrated with most of the communication that took place between patients and providers being mainly instrumental (cure-orientated). In other words communication was mainly related to the task in hand e.g. exchanging information, conducting physical examinations, reviewing and prescribing treatment. The nature of the patient-provider relationships observed were largely domineering and there was barely any display of 'friendly exchanges' or concern. However the communicative stream is complex and some messages may assume more salience than

others depending on patients and providers respective goals and expectations (Street, 1991). For example 'instrumental' exchanges may take on an affective or empathic dimension because of its significance to the patient. In this study there appeared to be no obvious examples of this taking place.

In the consultations observed as part of this thesis, a language barrier was identified which caused conversations to breakdown, patients and providers to talk at cross-purposes and information to be misunderstood by both parties. However, had these consultations been analysed in isolation of the patient and provider interviews and these interviews in isolation from each other then, like the authors of the studies described above, I might well have assumed that it was simply a language barrier that caused these difficulties and, as such, prevented communication from being effective. Additionally, comparing interpreter-mediated interactions with consultations in which patients attended alone revealed to me that the reasons why these consultations are problematic are not simply to do with a language barrier. Whilst I am not suggesting that language barrier is not a problem, I am arguing that it has perhaps become a reason on which to hang all the problems associated with cross-cultural consultations whereas my study has revealed that matters may be much more complex.

## **10.4 Undisclosed agendas**

One of the key findings from this study was that, irrespective of patients' language skills and whether they were accompanied by an interpreter or not, many of these patients were not disclosing information/concerns/issues that may have been relevant to their diabetes consultations and the treatment decisions subsequently made. Similar findings have come out of Bell et al.'s (2001) study who administered patient surveys before, immediately after, and two weeks after patient self-referred visits to practice clinics in California. They found that a proportion of patients, especially the young, uneducated, and unmarried had one or more 'unvoiced desire' and noted that desires for referral and physical therapy were least likely to be communicated. Similarly, Barry et al. (2000) observed British general practice consultations with patients who they had interviewed before and after these consultations and they also found that many patients left their consultations with at least one 'unvoiced agenda'. More recently, Tjia et al (2007), interviewed older (above age 65) patients with T2DM in order to explore their concerns about the complexity of their drug regimens and, to determine whether they discussed medication-related concerns with their physicians. They found that while most respondents described physician-initiated discussions about adherence

and side-effects, many did not bring up concerns about medication cost or their desire to reduce medication burden with their physicians. These studies highlight that the issue of patients not raising concerns and/or asking questions may be generic to all consultations and, irrespective of the kind of patient attending, transcend any language and cultural differences.

Bell et al. (2001) argue that this phenomenon is likely to be a widespread feature of the patient-provider interaction but methodological limitations in their study, may have under-exposed this issue. They explain, for instance, that some patients may have been hesitant to report that they did not 'stand up for themselves' by communicating their expectations to the healthcare professional because they were "saving face". Barry et al. (2000) elaborate on this point by suggesting that patients may also be, as Bell et al. (2001) put it, 'managing impressions' in their consultation by behaving as they believe they are expected to rather than as they would like. In other words, patients assessed, evaluated and voiced those agendas in terms of what they thought their providers would most likely want to hear and had perhaps learned over the course of their past consultation experiences that the 'life-world' (Mishler, 1984) has no welcome place in medical consultations. Tjia et al. (2007) in their study involving patients with T2DM also suggest that patients may not discuss issues with their physicians because they think their concern is not important enough and also that a lack of time during the medical encounter may discourage them from doing so. In the current study, patients were seen to have complex and, sometimes difficult, personal and health-related circumstances which impacted upon the way in which they managed their disease, yet this information was seldom shared with their providers.

Barry et al.'s (2000) and Bell et al.'s (2001) discussion can be taken forward in light of the findings from this thesis. Patients in this study provided a number of reasons for why they had not raised some of their issues concerning their diabetes. Some patients said that they felt it was more appropriate to discuss these with their GPs who, unlike hospital doctors, were seen to have some knowledge about their health-related history. Other patients claimed they had simply 'forgotten' to mention these things to their providers but this explanation did not add up with what they had previously told me and with the ways they behaved during their consultations. It is likely that these patients were also 'managing impressions' with me, an issue to which I will return to later in the chapter when I reflect upon the methodological implications of this study. Beyond the reasons provided by patients, their interviews with me also revealed how limited and narrow their expectations of diabetes consultations were

which largely centred upon their blood test results and advice relating to their medication, despite many of them having other diabetes-related concerns and issues.

Although researchers recognise that patient-provider communication is a critically important element of effective chronic illness care (Thorne et al. 2003; Michie et al. 2003) the findings from this thesis suggest that patients' diabetes –related limited expectations, which may be shaped by the structure and content of these review consultations, may in actual fact be hindering the communication process. Both Barry et al. (2000) and Bell et al. (2001) examined 'unvoiced agendas/desires' in the context of self-referred general practice consultations. They surmise that patients may be driven by a motivation for a diagnosis and/or treatment, especially if they are feeling poorly and perhaps prioritise what they will or will not raise in their consultations to achieve their goals in the limited time available. The findings from this thesis suggest that the motivation for patients attending hospital review appointments may be slightly different and in order to understand why patients were not disclosing relevant issues the process of these consultations need to be taken into consideration.

## **10.5 Lack of continuity discourages patients' agendas from being voiced**

There are several reasons that may have discouraged patients from raising their issues and worries including a lack of continuity in their care. Firstly, the frequency of these diabetes review appointments varied depending on the severity of the patient's condition and it was the providers who decided when the patient would next be recalled. Secondly, because of the inflexible arrangement of these consultations, if patients had any problems related to their diabetes in the interim, they would need to see their GP. Thirdly, these consultations were seen to offer little continuity and patients ended up seeing different providers because of the complexity of hospital structures, shift work and staff rotation (see Pooley et al. 2001). Fourthly, these appointments appeared disjointed partly because providers did not always have a record of patients' medication and had to rely on patients telling/or showing them which medication they were taking.

Bearing in mind that the consultation set-up may be different in Lothian where this study was conducted than in other parts of the UK, this study does provide some clues which may explain why patients in this study had 'unvoiced agendas'. Van Dulmen et al. (1997)



suggest that the first consultation between newly diagnosed patients with T2DM and their providers is the most important for building an effective doctor-patient relationship because the interaction is more equal and reciprocal and may create the foundations for a trusting relationship. They assert that during initial consultations more effort is put into establishing the relationship and once it is established less effort is put into maintaining it but do not provide any reason for why this may be. Nevertheless, if patients are continually consulting with different providers then continuity may be lost. It has been reported by Alazari et al. (2007), in their health professional interview study, that patients with diabetes can often become confused and isolated when they consult several team members because the elements of trust, confidence and good rapport are not given the chance to develop. Taking further Alazari et al.'s (2007) claim that a good rapport is hindered when patients are required to consult several different health professionals, in this study some patients also said that they acted differently in their GP consultations compared with their infrequent diabetes review appointments and that they were more likely to talk frankly with someone they had become acquainted with rather than a stranger. The point to be made here is that patients may act differently in different types of consultations. Since consultation research has predominantly focussed on self-referred general practice consultations we have a limited understanding of how patients perceive and experience review consultations undertaken by different providers. Also, this thesis has shown that, many patients irrespective of a language barrier, had limited diabetes-related expectations of their review consultations which centred upon monitoring and evaluation. These expectations may have been shaped by the lack of continuity in their care which may have discouraged patients' agendas from being voiced and/or facilitated. Thus, it is important to bear in mind the type of consultation and the setting in which it occurs when exploring the reasons behind patients' unvoiced agendas.

An alternative explanation which may help understand why these Pakistani patients did not voice their agendas can be traced back to their experiences of healthcare in their original homelands. These patients may have cultivated a set of values and understandings from their past experiences in Pakistan which they may have brought to their consultations in the UK. As was described in more detail in Chapter Two, privacy and confidentiality issues during the patient-doctor interaction are not considered as important in the Indian subcontinent as they are in Western societies and, typically, on the Indian subcontinent consultations are conducted in front of other waiting patients (Saradamma et al. 2000). Perhaps patients in my study were particularly averse to raising their personal concerns or matters because they may

have become used to a different way, to White patients, of presenting themselves and relating to the doctor. Given the context in which their past consultations may have occurred, Pakistani patients may have become accustomed to presenting very little of themselves, or their problem 'publicly' (Roberts et al. 2005). Also, because consultations in Pakistan are brief, patients intended outcome is to obtain a prescription. Indeed, in this study most patients were seen to come away with the same two messages: to do with their medication and, their test results and, as long as they achieved these messages they perceived their consultations to be successful. This may have been a reflection of what these patients had come to expect from their consultations, by virtue of their past experiences in their original homelands. However, there may be a further subtlety in the findings from this study which may also explain why patients did not voice their agendas.

## **10.6 Unvoiced agendas as a strategy to manage a language barrier**

The reason why some patients did not disclose their diabetes related concerns may simply have been because they were unable to speak sufficient English and therefore excluded concerns which were difficult to convey and which ranged from being serious (hypoglycaemic attacks), to less serious (questions relating to diet). It is also possible that patients did not voice their agendas as a strategy for preventing and managing misunderstandings. Had they chosen to speak of their concerns within the confines of their limited English, then their consultations might have taken a different course and may not have been considered as 'successful' both by these patients and their providers. This finding is supported by Roberts et al. (2005) who video-recorded cross-cultural consultations that took place in London general practices involving self-referred patients. The authors use the term 'low-self display' to describe strategies used by patients to direct attention away from their poor English skills and enable them to navigate their consultations 'successfully'. Roberts et al. (2005) found that some patients said little during their encounters but handed over a letter, some pills or even empty bottles and jars to show what their diet is like, and waited for the GP to infer what their problem was.

The authors explain that these physical actions can help patients keep a 'low self-display' which was a way in which they prevented misunderstandings by compensating for their limited English with documents and artefacts. Similarly, in this study, patients were seen to take along with them a bag containing their medication which they presented to their

providers when requested to do so. A fundamental difference between Roberts et al.'s (2005) and my study, however, was the type of consultation that patients were attending: the former study included emergency and routine general practice consultations. Returning to the point I made earlier, the type of consultation, whether self-referred or a rolling compulsory review, and the outcomes patients expect from these, may dictate what goes on in these consultations. Since diabetes review appointments tended to follow a standardised and predictable format, arguably, this made it possible for patients with a low proficiency in English to navigate it. By not disclosing their concerns and thereby exposing their poor English skills they ensured that information flow was largely one-directional (from the provider to the patient). Thus these strategies may not necessarily facilitate effective communication but enabled patients with limited English to 'get by' independently.

Another strategy that patients were seen to adopt to navigate their consultations, and, which is inextricably linked with the notion of 'unvoiced agendas' was their propensity to be passive in their encounters. As described above, one reason why many of the patients in this study may have been passive was because it enabled them to achieve the aims of their consultation both quickly and effectively. Some patients had complex thought- processes about, for example starting on insulin, which became apparent to me in my interviews; however they did not choose to make an issue of this in their consultation. As well as not raising their concerns, patients were often seen to remain quiet, express agreement with their health professionals, provide yes/no answers and not complicate matters by raising tangential issues. As Barry et al. (2000) point out patients can also be goal orientated and want to achieve their goals as quickly and as efficiently as possible. These strategies helped patients maintain low self-display and ensured that that the discussion did not stray out of their zone of comfort. However as I now go on to argue, passiveness may also have served another function, one which enabled patients to sustain some form of independence and control over their consultations.

## **10.7 Passive 'control'**

In this thesis, some healthcare professionals described how they found it difficult to consult with patients who came across as passive. They described feeling helpless as they were unable to build a rapport with these patients and, more crucially, they were unable to determine how much these patients had actually understood during these consultations. Some providers reported that they preferred patients to be a little 'resistant' to the advice they gave to them instead of too easily agreeing with everything that was said as this

indicated that they were taking in information. Whilst, for some patients being passive may well have been another strategy to manage a language difference, it may also have served as a means of keeping some degree of control over their consultations.

The notion of 'passive control', which could be considered to arise out of this thesis, may help to explain why patients who speak limited English are able to attend without being accompanied by an interpreter and also why healthcare professionals never really questioned their language skills. Passive control allowed patients to ascertain independence because they could achieve their pre-consultation expectations without assistance from anybody else. Indeed, providers were the ones who were frustrated by the lack of communication and were unable to find cause for it in a language difference. Given the time constraints of medical consultations, patients may be managing the time allocated to them by deferring to the providers' authority, as in this way, they are more likely to achieve their (albeit limited) aims quickly. In contrast, if patients brought all their issues to the fore, challenged/questioned providers advice and treatment, continuously asked for information, would they have achieved the same outcomes? Roberts et al. (2005), in their study about cross-cultural consultations also examined patient 'talk' and its potential for contributing to miscommunication. The authors introduce the notion of 'trouble' whereby problems of sustaining social interaction lead to uncomfortable, disruptive or confusing moments between the patient and their provider. They found that in cases where there was a language difference, it was more difficult for health professionals to assess where the problem lay when the level of talk caused more protracted, general and unresolved misunderstandings and during which patients and providers end up talking past each but not knowing quite why. Thus to guard against this 'trouble', I argue that it makes sense that patients would choose to remain passive and yet achieve some implicit control over the structure of their consultation.

However, the problem with patients doing this is that it may mislead their providers into thinking that perhaps a language difference does not exist because they were not fully aware of how little of what they said was understood by them. Indeed this was seen to be the case in the current study as, despite my observation of there being a language barrier in some consultations; health professionals would instead assign communication difficulties to other non-language barriers. Arguably, patient passivity may also reflect assumptions that the consultation is a hierarchical encounter in which the doctors are invested with considerable power (Roberts et al. 2005; Hunte and Sultana, 1992). Again, patients' past experiences of consultations in their original homelands and also of consultations in the UK may also be

used to explain their passive behaviour. Doctors practising in Pakistan are reported to display a highly directive and paternalistic consulting style and patients are deferent to their knowledge and expertise (Hunte and Sultana, 1992).

To summarise the above section, patients' passiveness may not only have served as a distraction from their poor English skills but also enabled them to achieve the aims of their consultations with relative ease and minimal 'trouble'. Although, their deference to providers' authoritarian role may partly be understood in terms of their past experiences of consultation hierarchies, it may also be a reflection of the political and racial tensions (Islamaphobia) which were heightened at the time of this research. Nevertheless, passiveness, although problematic, need not be entirely unconstructive, as it enabled and permitted patients to retain some 'control' over their consultations and with that a degree of dignity and independence.

In the following section, I will argue how the aforementioned strategies (unvoiced agendas and passiveness) used by patients, are in a sense, influenced by a desire to appear credible and valued in others as well as their health professionals eyes.

## **10.8 Impression management**

Bell et al. (2001), in their interview and observational study, suggest that patients may under-report the extent of their 'unvoiced desires' simply because they do not want to appear incompetent. Moss and Roberts (2005) explain that patients recognise that how they present themselves to the doctor is relevant to the outcomes of their consultation and how their concerns and interests are met. To further understand these patients' concerns, I will briefly draw upon Goffman's (1959) notion of 'self-presentation'. According to Goffman (1959) there are two main motives that govern self-presentation. What he terms 'instrumental motive' seeks to influence others to gain rewards/ desired outcomes. The second motive underlying self-presentation is expressive. We construct an image of ourselves to claim personal identity and present ourselves in a manner that is consistent with that image.

In this regard, Robert et al.'s (2005), 'low self-display' strategies and the strategies that were identified in this thesis (non-disclosure of information and passive control) may also be seen as a form of impression/identity management by patients in order to construct a positive self-image. For instance 'passive control' appeared to be both about face-saving (identity management governed by the expressive motive) and obtaining the basic things one needs

out of one's consultation (instrumental motive). In the current study, had the patients with poor English exposed their 'inadequacies' (in terms of their language) by attempting to be more active than perhaps the 'ceremonial order', that governs the form of relationship between patient and provider (Strong, 1979) might have been undermined. Indeed, it can be argued that it is the 'ceremonial order', in other words, the routine and predictable format of these consultations that partly enables patients to successfully manage their identities and impressions and fulfil their instrumental motives. In following the expected etiquette and the rules of conduct that govern this social interaction, it may have been possible for patients to camouflage their difficulties speaking and understanding English. Again, this was perhaps even simpler and easy to do in review appointments, in which the main purpose is to evaluate patients' condition, and in which the transmission of information can be one-directional (provider to patient). Self-referred patient consultations, which as I have pointed out earlier have tended to be the focus of most studies to date, have the added complexity of patients having to convey to the provider the purpose of their visit.

In this thesis, some healthcare professionals were uncertain about their patients' language skills, but because patients appeared to agree with most of what they said and followed requests made to them during their encounter with ease, such as being asked to take their shoes off so that their feet could be examined or asked to roll up their sleeve so that they could take a BP reading, providers often turned to other reasons or assumptions to explain why their patients were passive or inactive during their encounters.

Before I turn my attention to issues that relate to providers' communication styles, I will briefly summarise what has already been discussed. Even if language is a major barrier in these consultations, it may not even be recognised as such by providers. Patients with limited English could strategically manage their consultations independently and achieve their limited aims. The routine and predictable nature of these review consultations meant that patients could be passive and offer very little information and still 'get by'. Irrespective of a patient's language skills, the lack of health professional continuity in these diabetes consultations may make care delivery to these patients fragmented and further 'close' them off from being active participants in their consultations. Effective communication does not simply ensue even if patients and providers can speak the same language. Barriers also arose in language concordant consultations and could be explained in terms of some of the values and perceptions these patients had adopted as a consequence of their past consultation experiences both in the UK and in their original homelands. In this study, health

professionals' directive communication styles sometimes hindered patients with good/fluent English from being active participants in their consultation. Patients' careful management and negotiation of their consultations can also be understood as a product of the kinds of impression of themselves they wish to create on their providers. Where there are language/cultural differences, it is even harder for patients to manage their identities and appear competent in independently managing their consultations. However, this kind of impression management may come at a price and patients may compromise having their concerns appropriately addressed and hence may suffer from additional problems. Indeed, as I will discuss in the next section patients' concerns with not coming across as 'socially incompetent' Pakistanis, may be a genuine worry.

## 10.9 Negative stereotyping

Bowler (1993) carried out an ethnographic study which examined South Asian (predominantly Pakistani) women's maternity experiences in the UK and, as part of this, examined the stereotypes of these women held by midwives in a hospital. Interviews with midwives were compared to and contrasted with, observational data. Bowler (1993) also opportunistically engaged with some of these women's views during her observations. She found that 'negative typifications' were reinforced if women had poor English because midwives could more readily apply such stereotypes to women with whom they could not communicate. This resulted in the women, who spoke little English, as being labelled as unresponsive, rude and unintelligent. These stereotypes were further reinforced because it was difficult for women who spoke little English to make a personal relationship with the midwife and thus challenge any such stereotypes. Similarly, in this thesis, several of the providers explained their communication difficulties with their patients in terms of stereotypical assumptions. For instance, one provider suggested that his patient may have had a learning disability and, another explained that his patient was particularly passive because Muslim women are supposedly not permitted to talk frankly with men who are strangers. Another doctor assumed that Pakistani patients may be fatalistic towards their disease management because of their cultural beliefs. The women in Bowler's study got the sense that midwives saw them as "stupid" and "thick" and indeed this was sometimes true as Bowler illustrated in the following quote from a midwife:

*"Some Asian women are like blocks of wood, you know, thick [banging the side of her head]. Mind you others are delightful. It's impossible to know whether they've understood or not. [p.161]"*

Another midwife remarked:

*“They’re too stupid to remember when to come to the clinic”* [page 161].

However, unlike in Bowler’s study, the majority of the patients in the current study did not appear to think that their health professionals held stereotypical assumptions or negative opinions about them - in fact, many patients often praised their health professionals. Health professionals in this study, like in Bowler’s study, did indeed have some opinions about their Pakistani patients which were informed by the difficulties they experienced in communicating with them, but none made comments as severe as those illustrated in Bowler’s study. In fact, many of the health professionals in the current study seemed frustrated that they were not able to engage more fully with their patients and suggested that cultural differences may make it difficult for them to establish rapport with them.

In light of what has been discussed, I will briefly refer to patients’ communication strategies before returning back to discussing health professionals’ communication styles. Drawing on Ardener’s work (1972, 1975, 1989) Bowler explains that, in order to compensate or prevent or stand up to this kind of negative stereotyping, ‘subordinate groups’ may become ‘muted’ in interactions with the dominant order. He argues that it is not because they are ‘dumb’, but when such groups are faced with communication difficulties they often become ‘muted’ because they are not listened to, or if listened to, not understood. Adding to Ardener’s point, I have shown how patients in this study did not just become ‘muted’ or passive, they recognised the limitations of their language and had learnt to strategically negotiate answers and information from their providers. Again, the point needs to be emphasised that the type of consultation (review or self-referral) may affect how much ‘control’ patients may be able to exercise over their interactions. Also, since these patients were veterans in the consultations I observed, they may have already experienced some of the ‘negativity’ described by Bowler (1993) and, over time, learnt to temper, but not necessarily overcome, some of their communication difficulties.

The ways in which providers choose to communicate may also hinder effective communication. As noted in the previous paragraph, providers in this study sometimes spoke long and complex sentences, despite there being a language gap. In the following section, I will discuss how providers’ communication styles sometimes contributed towards the limitations of these cross-cultural consultations.



## 10.10 Providers' 'controlling' communication

Radley et al. (2008) observed video-taped consultations between physicians and patients with irritable bowel syndrome and, in their paper, provide contrasting examples of providers who used an 'interrogative' approach, common to many consultations or a 'patient-centred' style. They found that providers who asked more open ended questions, such as 'how are you?' and 'what are your feelings about that?', encouraged a patient centred-approach but the most frequent types of questions were closed ones to which a 'yes' or 'no' answer is expected. Similarly, many healthcare professionals who took part in my study were mostly seen to ask direct and closed questions which elicited short answers from their patients which was also evident when providers were required to communicate through interpreters. Providers' questions mainly focussed upon patients' blood test results, their medication and anything they thought they needed to know from the patient in relation to the physical examinations that they conducted.

According to the literature based upon language concordant consultations, this kind of directive or interrogative provider communication style is viewed as instrumental or task-related (e.g. giving directions, giving information, asking questions, asking clarification etc) (Willems et al. 2005). Providers who are 'affective' during these encounters (e.g. involved in more social talk, paraphrase and show concern etc) are more likely to engender patient involvement in the consultation process and have a positive influence on the outcomes of consultations (Ong et al. 2000; Street, 1992; Roter et al. 1988). Radley et al. (2008) argue that the instrumental and affective dimensions of providers' communications often co-exist in consultations depending on what is being discussed. Healthcare professionals are also reported to make communication less 'affective' when they use complex medical and technical terms without explaining their meaning to patients (Ong et al. 2000). This was evident in some of the consultations observed as part of this thesis. Even when a language gap existed and in some cases was clearly evident, it did not prevent providers from using medical terms and/or 'colloquialisms' that may not be understood by people belonging to other cultures. In this study, not only were health professionals seen to sometimes convey complex pieces of information to patients but very few health professionals were actually seen to have tried and establish whether patients understood their advice.

Providers' communication styles can be understood in the context of the structural and functional settings in which these consultations take place. By adopting a directive approach and using technical language providers are able to keep tight control over their interactions

and bring the consultation to an end in a timely fashion. However, Howie et al. (1991) contend that doctors who offer longer consultation times are able to identify and deal with more patient problems which result in greater satisfaction levels amongst patients. The authors explored the impact the length of the consultation had upon GP-patient communication in Lothian, by recording the consultation length and asking GPs to record notes of what was discussed after the consultation. Patients were asked to complete satisfaction surveys immediately after their consultations. They argue that shorter consultation times resulted in patient receiving less psycho-social support and health education and in poorer satisfaction levels. However, in the current study, irrespective of whether patients had longer consultation times (usually with nurses and dietitians) or shorter ones, all of them said that they perceived their consultations to be successful. 'Satisfaction' with, and/or perceived 'success' of their consultation are potentially 'loaded' terms and as I have highlighted in this study, through the use of a multi-method design, that relying solely on patients' accounts is simply not enough or adequate.

As well as to preserve valuable time, providers may behave in a controlling manner in response to patients' backgrounds and communication styles. Willems et al. (2005) systematically reviewed studies which explored whether patients' socio-economic status influences patient-provider communication. Their results showed that patients from lower social classes receive less positive socio-emotional utterances, a more directive and a less participatory consulting style. These differences in providers' communicative style can partly be explained by differences in patients' communication styles. For instance, patients from lower social classes tend to ask fewer questions, express fewer opinions and display less preference for decision making. This finding is consistent with findings from a study conducted by Street et al. (1993) involving patients with T2DM. They found that more educated patients engaged in more decision-making behaviours and received more patient-centred care. Although 'ethnicity' tends to get 'lumped' together with other patient characteristics (Nazroo, 1998), less is known about how ethnic minority patients communicate with their providers and, vice versa and how this compares with patients who share the same ethnicity as their providers.

In this thesis, I too have shown how communication between providers and their Pakistani patients was seen to be limited because it was largely 'instrumental' or 'task-related'. Providers had a directive approach, used complex language and communication was mostly one-directional. As previously discussed, patients passive and muted communicative styles

may encourage and reinforce this paternalistic model of communication. Additionally, patients' perceptions of providers negative stereotyping may further promote the typical paternalistic structure of the consultations observed as part of this study. To safeguard against provider misconceptions patients 'self-presentation' is primarily influenced by an instrumental, rather than the expressive motive. Given the evidence that the 'affective' component of the patient-provider interaction is crucial to establishing communication and which may result in positive outcomes, this study has highlighted how both patients and providers align their motives with the instrumental component of communication. In other words, the 'affective' component of communication, considered to be so vital to patient-provider rapport-building and shared communication is being compromised or minimised. Arguably then, the lack of 'affective' communication may be hindering effective communication in cross-cultural consultations. I argue this because in this study most patients' generally expressed 'satisfaction' with their consultation experiences suggesting that they were happy with what 'occurred' during them even if they did largely consist of 'instrumental' exchanges. This further reinforces the point that communication in these consultations is very complex, and, although some theoretical frameworks may be useful in providing an understanding into this interaction they cannot always explain some of the nuanced and more subtle exchanges that take place between patients and their healthcare professionals.

### **10.11 Structural and organisational constraints**

I have briefly referred to time as a physical barrier to effective communication. The consultations I observed usually lasted between 8 and 12 minutes with doctors and between 20 and 25 minutes with nurses and dietitians, and they were slightly longer if there was an interpreter involved. It is already recognised that in language concordant consultations, both time and funding constraints can act as disincentives for doctors to explore and respond to patients' preferences regarding the type of partnership they would prefer to have in the process of making decisions about treatment (Charles et al. 1999). Scambler (2003) notes that the pressures of time encourage a more tightly-controlled or 'paternalistic' consultation and less attention is paid to the social and psychological aspects of a patients' illness. Howie et al. (1991), as described previously, found in their study that patients' 'satisfaction' is linked with consultation length but their results are based on the controversial satisfaction measures and hence not useful in understanding why this may be the case. Scambler (2003) argues that increasing the time allocated to consultations does not facilitate a patient-centred

approach nor does it mean providers will change their consulting styles or that patients will feel more inclined to talk more openly. There is much more than simply the lack of time which may hinder effective communication. For instance in this study I have argued how the routine and structured order of these consultations may inhibit patients from raising their concerns and so the aims of the consultations are kept narrow. Unless other changes are made in the consultation simply increasing the time may mean that that providers and patients will do more of what they are currently doing and not really changing their communication styles.

In the following section, I move onto discussing the last set of findings from this thesis and which pertain to interpreter-mediated consultations.

### **10.12 Do interpreters ‘improve’ communication between patients and their providers?**

The number of consultations observed involving interpreters in this study were small so any generalisations are made with caution. However, by virtue of using a case study approach, it was possible to explore some of complexities and nuances that arise from a triadic interaction and how this may affect communication between patients and their providers. Many of the issues that were identified in the non-interpreted consultations were also found in the interpreter-mediated consultations. For instance, patients attending with interpreters had similar, albeit limited, expectations to those patients attending without interpreters, and patients sometimes did not raise their diabetes-related concerns despite having the aid of an interpreter. Indeed, as I have already discussed, shared language does not necessarily improve communication in these consultations so a superficial analysis might be that interpreters were simply not adding to, or subtracting from, these consultations. What my study showed was that in actual fact interpreters substantially influenced these encounters and introduced a whole plethora of other issues and sometimes problems into these cross-cultural consultations.

Numerous studies report that professional interpreters have a positive influence upon, and can improve, the quality of communication between patients and providers (Karliner et al. 2007; Jacobs et al. 2007). Karliner et al. (2007) conducted a systematic review of studies which reported the impact of interpreters upon communication. Only two of the 21 studies reviewed examined consultation interactions directly by audio-taping the encounter and 18

of these studies were quantitative. Results were largely based upon patient satisfaction surveys and utilisation of interpreter services. The authors concluded that the use of trained professional interpreters is associated with improved communication and can be equivalent to communication in consultations where there is language concordance between patients and providers. Other studies (e.g. Cambridge, 1999) have shown how untrained interpreters can introduce communication errors into the consultation. Cambridge (1999) conducted discourse analysis on a series of simulated consultations between GPs and their non-English speaking patients and found that untrained interpreters sometimes edited information and caused information to become lost. Many studies (Flores, 2005; Vasquez and Javier, 1991; Garcia et al. 2004) advocate the use of professional interpreters instead of lay ones because they are less likely to cause errors in communication. However, Dysart-Gale (2005) explain that the interpreter traditionally has been conceptualised as a 'conduit' transmitting messages between parties reliably and without distortion. They argue that this is an over-simplified role as, in reality, interpreters are doing much more. These studies highlight some of uncertainties and contradictions in the research literature exploring the roles of, and impact of, interpreters.

Hsieh (2006, 2007) carried out an ethnographic study examining the roles of interpreters and some of the conflicts they may be faced with. She observed 12 triadic encounters between patients, their providers and Mandarin Chinese interpreters in the US and supplemented these observations with interpreter interviews. Hsieh found that professional interpreters were not simply neutral participants in medical encounters but assessed, reviewed and managed information and interpreted accordingly. This meant that interpreters were often seen to edit information, initiate information-seeking behaviours and volunteer medical information to the patients amongst other things. Interpreters justified this 'co-diagnostician' role by stating that providing quality health-care service is a team effort and they saw themselves as part of the medical team. Hsieh points out that this may be problematic as interpreters are not medical experts and therefore are in no position to judge the value of information.

Some of the findings from Hsieh's (2006, 2007) study resonated with what was found in this thesis. For instance, I observed how interpreters would edit information and one interpreter explained his behaviour in terms of looking out for the patient's best interests by guiding and supporting them through the consultation process. Whereas Hsieh's respondents felt that their roles were largely dictated by what went on during the consultations, interviews with

interpreters in my study highlighted how their relationship with the patient outside the consultation setting also had implications for how they interpret. The findings from my study were inevitably influenced by the ways in which the interpreters perceived my identity in relation to the local Pakistani community.

### **10.13 Interpreters as a resource for help and advice**

Hsieh (2006, 2007) speculates that interpreters' outsider roles also create challenges in the consultation because interpreters are sometimes motivated to seek information about the patient's medical history. She explains that it is possible that, by initiating information seeking when they are alone with the patient, an interpreter may be able to conduct the session with greater accuracy and efficiency. As mentioned previously, in the current study interpreters reported that it was common for patients to approach them for help and advice outside of their consultations. Sometimes patients would raise issues with their interpreters that they did not with their providers during their consultations. It has been reported that lay interpreters who are related to, or friends of, the patients can also play the role of caregiver and may be involved closely in the patients' lives (Rosenberg et al. 2007). Hence, it is understandable that patients often draw on these people as a resource for further help and information. In the current study my interviews with professional interpreters revealed how patients would approach them outside their consultations for clarification of what their provider advised, further advice and information, and sometimes patients would even ask interpreters to accompany them to future/ referral appointments. These findings may be partly specific to the context in which this study was undertaken. Interpreters in my study like their clients, belonged to the tightly-knit Pakistani community in Edinburgh, where people generally know each other or of each other. The more closely knit these communities are the more mutually supportive they tend to be of each other (Ballard, 2002). These relationships are partly borne out of people's sovereignty to religion and from their migration and settlement experiences (Jejeebhoy and Sathar, 2001). Shaw (2000), in her anthropological study of Oxford Pakistanis, found that migrants' initial dependence on each other for work, accommodation and welfare had the generally conservative effect of ensuring that they acted according to the expectations of kin in Pakistan. This means that British Pakistani form 'pseudo-kinship relationships' with non-kin Pakistanis in order to fulfil the roles performed by 'real' kin back in Pakistan. As a result of these ties and kinship obligations, people have expectations of fellow community members which transcend any 'professional' boundaries imposed by institutions such as the NHS. It is possible, therefore,

that professional interpreters operating in cities like Leicester or Bradford where there is a much larger South Asian community are less likely to be faced with these dilemmas because there is less chance that the interpreter and patient will be known to each other.

To summarise, I have discussed how effective communication in consultations is not simply achieved by language concordance. Although language is important differences in language cannot be considered the only reason that contributes to poor communication in consultations. The methodology adopted for this study enabled comparisons to be drawn between the consultation observations and patient/provider/interviews, interviews, the latter revealing how these interactions were also informed and shaped by structural constraints and patients' and providers' communication styles. Interpreters may ameliorate some of the communication problems that arise in cross-cultural consultations but may bring further miscommunication into these consultations, partly as a result of interpreter-patient relationships that exist outside the consultation setting. It is worth noting here that, although the analysis of the data from this thesis has resulted in findings that highlight the multitude of barriers that exist in these consultations, there was some, albeit limited examples of effective communication (see Chapter Eight). These included good eye contact between the consulting parties and short and simple spoken sentences to allow for information to be translated accurately. These findings underscore the significance of the communication style for the effective exchange of information. However, factors that facilitated communication were comparatively fewer than the barriers that were identified, a finding which further highlights the problematic nature of the cross-cultural consultation. The triangulation of methods enabled me to understand and explore the consultation interaction in the broader context in which it is situated and from different participants' perspectives. I will now provide some final reflections on the methodological design and the impact of my involvement in the research process.

## **10.14 Methodological reflections**

In this section I will reflect upon some of the strengths and limitations of the methodology adopted for this thesis. I will also provide some retrospective insights into the experiences of doing research amongst members of a largely migrant and close-knit Pakistani community.

### **10.14.1 My position as a Pakistani Muslim researcher**

Ramji (2008) provides a rich and interesting insight into the experience of researching British South Asian women's lives in London as a female British Asian researcher. This paper was influential, in highlighting to me the benefits, challenges and dilemmas that arose out of my own research. Being a member of the Pakistani community I was researching, I had a 'shared cultural identity' (Ramji, 2008) which helped my research, in so far as it helped in establishing the initial contacts to make what would eventually become my research sample. This can be contrasted with Edward's (1990) experiences who found that, as a White female researcher interviewing Afro-Caribbean women, she had difficulty recruiting respondents and engendered their suspicion. My name, my background, my accent, my fluency in Punjabi or Urdu, my appearance (skin colour) and how I dressed, are just some of the things that enabled common reference points between these respondents and me. As a Scottish Pakistani female researcher I was particularly conscious of the way I might come across to my male respondents, who belonged to a generation older than mine and had migrated from Pakistan. Based on my own personal experiences, I was aware that these men may hold traditional cultural values especially about women in terms of female modesty. Certainly, I did not want to appear 'Westernised' and as someone who was not in touch with her cultural roots at risk of isolating or even offending my participants. This self-consciousness did not ease as data collection progressed, partly because my interactions with these men reinforced my views. In order to make myself and my respondents feel comfortable and relaxed during these interviews, I wore traditional Pakistani dress and, with my male respondents, a long heavy coat over it even in the middle of the summer as this level of modesty gave me personal confidence to interact with them. Researching in a close-knit community where everyone knows each other or of each other, had a bearing upon the interaction. Respondents who made a connection with me (for instance through knowing my parents) would start calling me 'beti' (daughter) and so the relationship would shift from researcher-interviewee to (honorary) daughter- mother/father. These respondents appeared to talk more enthusiastically but at the same time they may have become more susceptible to 'face-saving exercises' or 'impression management' because I was connected to, and moved within their community and were more likely to expect my help in the consultations.

Being a Pakistani perhaps also helped my access to, and recruitment of, healthcare professionals, who were all White. Some providers, especially those who had an interest in ethnic minority care delivery, went out their way to help with me with recruiting and data collection. Although, their efforts can be considered as nothing less than genuine, they may



have perceived that taking part in research conducted by a Pakistani may bolster their image and reputation amongst the Pakistani community and amongst other healthcare researchers.

Researchers are morally-engaged and come to the field with their own set of values and assumptions. Ahmad (2003) accuses native researchers of not possessing the same level of objectivity as a non-native researcher because their cultural/ethnic identity may mean they are too close to the subject matter to form an 'objective' view. Although I made every effort to be as objective as possible, inevitably I may have made judgements on how to present the data which portrayed these Pakistani patients in a favourable light. Naturally, I was sympathetic towards 'my own people' because of my own cultural background, and would have been less inclined to criticise their actions. However, this was kept under check by White researchers (my supervisors) reading my data and chapter drafts who were able to spot these fallibilities and encouraged me to self-reflect.

'Ethnic matching' has been advocated by Papadopoulou and Lees (2002) as a strategy to avoid some of the pitfalls that arise from 'unmatched' researcher-respondent pairs. Ramji (2008) contests this by arguing that 'matching' the researcher and the researched does not always promote a greater likelihood of accessing information and establishing a more egalitarian approach. A shared identity may in actual fact sometimes hinder disclosure of information. Indeed patients would find it odd if I asked them questions about their culture and their actions within these cultural norms because they saw me as belonging to, and therefore understanding, their culture. Sometimes it was possible to address this problem when I explained to respondents how it was important for them to elaborate on their points and offer me detail because for the benefit of non-Pakistani researchers and health professionals. However, doing this felt unnatural and respondents would continue to explain things to me as if it were tacit knowledge. I also found that post-consultation reflections with patients were sometimes tricky as they would not elaborate/explain their answers because they felt that I had seen everything for myself. Video-recording the consultations instead of personally observing them may have been an option to prevent this from happening, however there are disadvantages to recording the consultation in this way (see chapter three). Besides, one could argue that such a scenario in which patients asked for my help is indicative of patients' needs or a lack in service provision which may not have come to the fore had my presence been replaced by a video-recorder.

### **10.14.2 Narrative reconstruction**

During data collection, I also noted how some patients provided contradictory accounts between their pre- and post-consultation interviews. For instance, some patients would play down some of their health concerns and problems in their second interview with me after discussing them at great lengths in their first interview. In some instances, patients would become more open and frank in their second interviews whilst other patients would become ‘closed off’ or inaccessible to me. There are several reasons to explain why this may have been the case. The first reason is that patients may have reassessed their narratives in light of what happened during their consultations. For instance, some patients in their pre-consultation interviews complained about health-related issues and concerns that they had wanted resolved. Some even asked me to help them obtain a solution. Often these patients left the consultations with their issues unresolved, but instead of talking about why this may have been the case they showed comparatively little interest in talking about them or would even say that these problems no longer existed. This kind of narrative re-construction (Williams, 1984) could be understood in terms of ‘impression management’ (Goffman, 1959) strategies. It is possible that patients did not wish to draw attention to the fact that they had been unsuccessful in raising their concerns in the consultation and risk appearing ‘incompetent’ to me. Given that there was a possibility that I moved within the same community circles that they did, they may have been worried that I might impart negative opinions about them to other members of their community. An alternative explanation may be that some of the issues that patients highlighted as problematic in their pre-consultation interviews may have been perceived as less so after their consultation interaction. Patients may have reassessed the severity of their problem in light of what they experienced in their consultation (As summarised in Chapter Nine).

### **10.14.3 Methodological strengths**

As extensively described in chapter four, this research design is innovative and a novel way of tapping into the ‘social reality’ of the consultation. It enabled comparisons to be drawn between what happened in the consultations with pre- and post-consultation accounts and it revealed the patient-provider interaction to be a highly complex, dynamic and multi-layered phenomenon. Barry et al. (2000) point out that, in the study of medical interactions, researchers have typically chosen between interviewing providers about what they do and interviewing patients about how they respond to medical treatment. In this study, the use of multiple methods helped to situate the consultation interaction in a much broader context

than would have been possible had only one method been used. For instance, had I only relied on patients' interview accounts, one of the conclusions I may have drawn would be that patients were managing their consultations without much difficulty given their generally positive views about their consultation experiences. However, my observations often revealed a contradictory and contrasting picture to the one these patients portrayed and revealed how their consultations were often riddled with misunderstandings and miscommunication. Additionally, providers' and interpreters' (when one was involved) views and experiences were also explored which further enhanced the thoroughness (rigour) and the strength (validity) of this research design. In providing an opportunity for all the participants and not just the patients to give their accounts and views about their experiences not only was the consultation interaction explored thoroughly but their perspectives on the same consultation could be then be compared.

This research design was further enhanced and the methodology strengthened because of my language skills. Since I am fluent in English, Urdu and Punjabi I had the advantage of collecting the data first hand instead of through an interpreter, as is the case in some cross-cultural studies (i.e. Rhodes and Nocon, 2003). My ability to speak fluent Punjabi/Urdu helped me to establish a good rapport with my Pakistani patients and may also have helped the retention of these patients in the study to enable the completion of each case study. For instance, a patient who had opted-in to the study changed his mind about taking part as he thought during my initial call to him that I belonged to a community group and was being 'nosey'. Since, I was able to empathise with his views in his first language Punjabi, I quickly built a rapport with him and he decided to take part in the study.

#### **10.14.4 Methodological limitations**

Case study research has been criticised for its lack of generalisability because the use of small sample sizes (Abercrombie et al. 1984). In this study a small number of Pakistani patients were included and one might argue that beyond the study's sample, the findings may only be generalisable or relevant to those Pakistanis originating from the Punjab region of Pakistan and possibly also to those attending diabetes consultations and living in Edinburgh. However, Flyvbjerg (2006) argues:

*"In case study research the objective is to achieve the greatest possible amount of information on a given phenomenon, a representative case or a random sample may not be the most appropriate strategy. This is because the typical or average case is often not the richest in information...it is*

*often more important to clarify the deeper causes behind a given problem and its consequences than to describe the symptoms of the problem and how frequently they occur” [p.229]*

In this thesis each case study added new or different insights into the consultation interaction but also some key findings and issues did cut across at least some of them. Given that this area of study is currently under-researched, the case study methodology was appropriate because it helped to uncover understandings and insights that had yet to be realised such as nuances in the dialogue between the Pakistani patients in this study and their providers. Thus the findings from this study are not expected to be used for ‘formal generalisation’ but as a means to offer insights into the cross-cultural consultation such as the way in which some patients managed their consultations despite their poor English.

This methodological design was very time and resource intensive requiring a substantial amount of time and effort to undertake data collection, analysis and write-up of the findings. Whilst, it was possible to execute this study design as part of a doctoral study, it may not be realistic or feasible to do so in other situations. In this study, a substantial amount of time was devoted to co-ordinating pre-and post –consultation interviews and observations with a ‘hard-to-reach’ community group.

This kind of study is also quite logistically challenging to deliver. The successful compilation of each case study, for instance, required each component part of it to be collected and in the correct order. In one instance, I had interviewed a patient before their consultation, however the GP she was seeing refused to take part in the study and, as a consequence, I was not able to observe her consultation or interview the GP. I did interview the patient after her consultation however, but this dataset was incomplete and therefore incomparable with the complete case studies. In another instance, a patient refused to be tape recorded during his interview and his consultation but permitted me to take notes. Although I still used this case study, and spoke into a digital recorder soon after these events occurred to record my impressions and recollections of them I did not have any transcripts to work with. Researchers conducting a similar methodological design may need to be aware that they may acquire incomplete case studies and factor this in when drawing up their recruitment strategies. Additionally, I had to stagger data-collection to avoid situations such as needing to be in two places at the same time. In some cases patients opted-in but I was unable to include them in the study because their consultation was not scheduled for a time which was feasible for me. Furthermore, as described in chapter four (Study Design) I

needed to analyse case studies during the data-collection period and not only were they time-consuming to collect but also to translate/transcribe and analyse, hence this required data collection to be staggered over quite a long period of time.

In the following section of this chapter I will, in light of the findings that arose from this study, provide some recommendations for ways in which some aspects of the cross-cultural consultations may be improved so that communication is more effective.

## **10.15 Policy and practice recommendations**

### **10.15.1 Educate patients to make better use of their consultations**

Given the finding from this study that Pakistani patients have limited expectations of their consultations and that very few of these patients held ‘agendas’ other than receiving test results and medication reviews, perhaps we need to consider educating or re-educating these patients about what they can bring to and expect to gain from their appointments.

Communication can only be made effective in these consultations if patients have an understanding of how their actions or inactions may affect the outcomes. Hence, patients may benefit from being provided with both oral and written (translated) information clearly explaining the purpose of their consultations and encouraging them to adopt a more active role. There is some evidence which suggests that patients are more likely to ask questions, raise their concerns and request clarification or check understanding if they receive coaching before their consultations (Greenfield et al. 1985; McCann and Weinman, 1996). Harrington et al. (2004) reviewed the literature examining intervention studies (primarily randomised control trials) designed to increase patients’ participation in medical consultations and came to the conclusion that delivering interventions immediately before the patient’s appointment through face-to-face coaching, in most cases, encouraged patients to be more active in their consultations. Arguably, this type of intervention might be less effective with patients with limited English skills and those who communicate through an interpreter but if coaching/education programmes were tailored towards ethnic minority groups and were delivered in the language of their choice it may empower patients to take the initiative and also go into consultation with realistic expectations.

### **10.15.2 Provide continuity of care**

This study has raised the issue of how a lack of continuity in care for these patients may be hindering effective communication in these consultations. For example, some patients felt that seeing different health professionals for their diabetes care deterred them from raising issues and concerns that might be relevant to their consultations. The majority of these patients had their diabetes review consultations in hospitals, a situation which may not apply across the UK, since routine diabetes care and diabetes reviews are increasingly being devolved to primary care settings (Lawton et al. 2009). Due to staff rotation in hospitals there was a high possibility that patients in this study often consulted with different providers. The literature around consultations emphasises the need for an established patient-provider relationship as familiarity with one another opens up channels for effective communication (Matthews et al. 2009). It is even more imperative that Pakistani patients, especially those with limited English, have the opportunity to build up a trusting and long-term relationship with healthcare professionals who provide their diabetes care. This point is supported by the finding from this study that some patients justified why they did not discuss their concerns and issues with their hospital consultants because they preferred to do so with their GPs with whom they had a long-standing relationship.

There needs to be a systematic approach that ensures that, as much as possible, patients are seen by the same provider regardless of how frequent/infrequent these consultations may be. Saying this, there is the potential for greater continuity of care arising from devolvement of diabetes care to general practice in the UK, however it may be that the person a patient sees for diabetes care in general practice (the lead GP or nurse for diabetes) may not be their normal or preferred GP (Lawton et al. 2009).

To ensure that a productive and trusting relationship is developed between patients and their diabetes care providers, cultural mediators or liaison officers may act to bridge some of the differences between them (Gillam and Levenson, 1999). These bi-lingual mediators could evaluate the quality of these consultations using simple criteria. For instance, they could observe whether health professionals asked patients to summarise the main points arising from the consultation and how pro-active patients are in asking questions and asserting themselves. Based on these results the mediator could offer specific and relevant advice to both patients and providers on what may be improved in future consultations.

However, it is recognised that this may be a costly set-up and some may argue that increasingly more Pakistanis are speaking English, by virtue of being resident in Britain for several years and also because the second and third generation British-born Pakistanis are gradually outnumbering first-generation migrants. However, this study has shown that barriers to effective communication are not simply related to language. Shaw (2000), who studied the Pakistani community in Oxford, makes the point that:

*“Many beliefs and values and ways of acting and thinking have shown remarkable resilience even among the younger generation (the children and the grandchildren of the pioneer migrants). The younger generations especially have confronted, questioned and re-interpreted previously taken-for-granted beliefs, values and practices, but they have not necessarily or in any simple way assimilated Western beliefs and values.”*

Irrespective of language, people's values and belief systems may hinder effective communication. For instance, a British-born Pakistani, fluent in English and brought up in a traditional Pakistani family setting in the UK, may not agree or see the relevance of the dietary advice given to him or her and disregard it. A British-born Pakistani named Mr Mirza (see Chapter 9) who took part in this study told me that he observed some of the dietary advice that health professionals provided but felt that a “good hearty curry” was a necessity in his diet as he “grew up eating it”. Thus patients and providers need to work in tandem to implement effective but realistic and sensitive self-management regimens.

### **10.15.3 Educating providers**

Healthcare providers in this study often used complex language and difficult terminology even when it was evident that there was a language barrier. This was not helped by the fact that patients did not reveal how much or little they had understood or did not seek clarification. Healthcare providers working with Pakistani patients should always endeavour to use simple language and avoid as much as possible the use of complex terminology to safeguard against potential misunderstandings. It appeared from this study that healthcare providers may have little means of establishing patients' competency in English, especially if they are passive and not very communicative. It is important for providers to bear in mind that patients may not fully understand their discussion and should seek alternate ways to ensure that information is understood. For instance, if a provider intends on giving lifestyle related advice to help a patient to improve his or her blood glucose, then instead of just verbally asking them to undertake more physical activity and/or to reduce high fat foods in their diet they could reinforce these messages by using visual materials. Support for this

recommendation comes from Ngoh and Sheperd (1997) who designed culturally sensitive visual aids to help convey drug information to illiterate women and found respondents who received visual aids had a better understanding of their treatment than the group who received the standard advice with no visual aids. Similar materials designed by people who have an understanding of Pakistani culture and values could be used specifically in diabetes consultations involving Pakistani patients. Pictures and diagrams showing the effect of a patient's actions or inactions on their diabetes control may make more of an impact especially if they are accompanied by simple and clear messages written in Urdu. Recognising the common difficulties that providers encounter in terms of these patients' diabetes control a package of information related to different scenarios could be put together that providers could pick and choose from depending on the nature of the patients' condition. Once a good set of materials and aids are developed, this could be a cost-effective way of ensuring that at the very least the basic messages about diabetes management are not missed by these patients. Although it is important to bear in mind that some older Pakistanis are illiterate and in these cases visual materials may be used more than written ones. Before any written or visual materials are used in the consultation it would be beneficial that people who can suggest possible improvements to these materials can evaluate them, particularly amongst Pakistani patients with low literacy.

Further to this, healthcare providers should always establish if patients have understood the main messages arising from the consultation by asking them to summarise these messages at the end of the consultation and not assume that, just because a patient expressed agreement that they have actually understood (Lawton et al. 2006a). In fact, providers should be encouraged to engage in a more open discussion with patients at the outset of the consultation and encourage patients to converse with them so that they may establish how competent they are in their English skills (Lawton et al. 2006a). Several patients in this study said that they could understand what the provider said to them but it was answering them back in English which they found the most difficult. This predicament needs to be addressed as it will only serve to reinforce and sustain the hierarchical nature of these consultations.

#### **10.15.4 Recording and reviewing patients' medication**

In this study it was often observed that providers at the hospitals would ask patients to provide them with information relating to their medication. Some patients brought their medication with them and others recalled the names of their pills/insulin from memory. There appeared to be a reliance on patients for this important information which was



sometimes mis-conveyed leading to inappropriate treatment decisions. Saying this however, this problem is currently being resolved and a new system will be in place which ensures that patients' treatment information is accessible by their providers on a shared computer system thus patient information will be more integrated. However, there is one drawback to providers having patients' current treatment information to hand; patients would no longer need to tell this information to their providers themselves. There may be a risk that if patients are not taking their medication correctly because of a misunderstanding then this may be missed. A recommendation would be to ask the patients what medication they are on and when they are taking them and corroborate this information with the information that is held on the electronic record. This strategy may help identify patient misunderstandings regarding their treatment advice.

#### **10.15.5 Improving triadic consultations**

This study provides us with an indication that there is little consistency between the interpreting styles of different professional interpreters. Evaluation measures need to be implemented and consistent guidelines provided to professional interpreters to ensure that they are facilitating effective communication between their clients. This study also highlighted the significance of the relationship between interpreters and patients for the consultation interaction. Interpreters do more than just translate and may provide help and guidance to patients who ask for it. As suggested by other studies, bi-lingual health link-workers, who are people that provide a cultural bridge between patients and health professionals by acting as mediators, may be able to offer the support that these patients need (Lawton et al.2006a; Gillam and Levenson, 1999). Given that the prevalence of T2DM amongst UK South Asians is a serious and growing concern, it would make sense to invest finances in training up professional interpreters to specialise in diabetes care who would then be able to provide support and guidance to these patients. Although the consultation is the mainstay of diabetes care, it is clear that a more collaborative and culturally sensitive approach needs to be used in conjunction with it so that patients have a continual network of support outside of the consultation setting. Again, bi-lingual link-workers may be trained to encompass the roles of support-givers and of professional interpreter.

## **10.16 The direction of existing policy and the relevance of this study**

This study was done in light of the growing concerns around T2DM amongst South Asians living in UK. Poor T2DM knowledge levels, poor self-management and growing rates of mortality and morbidity amongst South Asians are some of the problems which need to be tackled. In Scotland several collaborations and working groups have been formed in order to improve diabetes care for ethnic minority patients, to raise awareness about this disease and to help reduce the growing rates of diabetes by implementing preventative measures. This is partly in response to the Race Relations (Amendment) Act (2000) in which required named public authorities, including health authorities, to remove discrimination and the possibility of discrimination; and to actively promote race equality. The implications of this act upon healthcare service delivery is that high quality services need to be delivered to individuals irrespective of their ethnic origins. The National Service Framework for Diabetes Delivery Strategy (2002) was drawn up to ensure proper and effective care to all patients with this condition and, to take forward what was in the framework, the National Resource Centre for Minority Ethnic Minority Health (NRCEMH) in Scotland was formed in 2003 which focussed on the needs of ethnic minority groups. The NRCEMH set itself six objectives; one of them is to identify the difficulties and barriers experienced by ethnic minority users of healthcare and in delivering care to these patients.

Over recent years there have been a number of activities that have taken place in Edinburgh to address health-related issues in ethnic minority groups, such as the 'Khush Dil' (happy heart) project funded by the British Heart Foundation. The project worked to address coronary heart disease and diabetes problems in the South Asian population in Edinburgh with an emphasis on prevention. Similarly, the Prevention of Diabetes and Obesity in South Asians (PODOSA) study, funded by the National Prevention Research Initiative and supported by a range of government and charity funders, led by the Medical Research Council, is explaining ways to prevent diabetes in Indians and Pakistanis living in Edinburgh and Glasgow.

Diabetes UK, in collaboration with the South Asian Health Foundation, compiled a review of recent research in this area and provides recommendations for future research. It suggests the need for more qualitative studies which may find ways to improve self-management and

education for people with T2DM with a focus upon increasing engagement in, and uptake of, educational initiatives.

Whilst the prevention of diabetes is important both economically and in order to improve the health of future generations, we still need to tackle the issue of poor self- management by patients who are suffering from diabetes. However, not only is the prevalence of diabetes increasing amongst South Asians but also, despite the educational initiatives to promote better diabetes management, the outlook still remains bleak (Diabetes UK and The South Asian foundation, 2009). To help improve knowledge and awareness of diabetes in the local community several educational initiatives have been trialled. The Minority Ethnic Health Inclusion Project (MEHIP), in collaboration with the Local Health Care Cooperative (LHCC) held two 'Health Fairs' in Edinburgh's central mosque for Muslims in 2003. Ghouri (2003) reports that these 'health fairs' were 'well received' because many people attended them. Evaluation of this initiative was based upon how many blood glucose and pressure checks were carried out. Such community-based initiatives are perhaps over-rated as they not only exclude the 'hard-to-reach' people belonging to ethnic minority groups but also because it is difficult to assess whether people are actually engaging at a level that will impact upon their self-management strategies or are they simply 'turning up'. Another issue to consider at this point is that several community-based initiatives like 'Khush Dil' tend only to get short-term funding but fail to get 'mainstreamed' in the long-term and thus cannot be relied upon as a part of patients' mainstream healthcare.

It seems concerning that in all of the above initiatives the diabetes consultation seems to be overlooked as an area for improving communication and patient engagement. Clearly there is an argument to be made here about targeting effort/research resources to making consultations "work well" as these other initiatives cannot be relied upon, whereas patients will always get reviewed. Since all patients with diabetes are invited at least annually to a diabetes review where better can this take place than in the diabetes consultation. Arguably, better use needs to be made of the resources and services that are already available. We need to take a step back and develop strategies that will enhance communication, build strong, collaborative and trusting relationships between patients and healthcare providers in which mutual respect is encouraged. More attention needs to be paid to how patients' diabetes knowledge levels can be improved in the consultation setting which is a valuable opportunity for a one-to-one interactive session with individual patients.

## 10.17 Recommendations for future research

This study primarily focussed on communication between Pakistani patients and their providers. There are many other areas where further research needs to be done in order to better our understanding of the quality of healthcare delivered to ethnic minority patients and gain a holistic picture of care delivery.

Some of the findings that arose from this thesis were related to a language barrier but other findings such as patients' passive control and their tendency to sometimes omit issues relevant to their consultations may cut across all types of consultations involving all types of patients. Communication is paramount if patients and providers are to engage in a meaningful and productive dialogue. A similar study to the one carried out for this doctoral research but with White patients would begin to give an idea of the diversity and extent of the communication problems in consultations as a whole. A comparative study would also be useful in further highlighting why the quality of communication in cross-cultural consultations can be poor by revealing what is missing or not happening in these consultations.

Although diabetes healthcare services are being devolved into general practice there will always be some patients who are referred to hospital e.g. those patients transitioning to insulin. By comparing consultations in different settings it may be possible to explore whether continuity of care is being offered in general practice consultations compared with hospital consultations and whether this is a positive influence on the patient-provider relationship. A future study could also involve observing a series of consultations between the same patient and health professional to obtain a more longitudinal insight into the patient-provider relationship. By following a patient through more than one consultation it might be possible to investigate how long-term issues and problems such as poor dietary control are dealt with in these interactions and the kinds of approaches providers use to tackle (or not as the case may be) these issues. In this study, patients often did not raise issues with their health professionals that may have been relevant to their diabetes care. Arguably, patients' 'non-disclosure' may have been artefact of the ways in which health professionals had dealt with these matters in the past and, perhaps in ways that may have been insensitive to patients' life circumstances. This aspect could be better explored if patients were observed more than once in these consultations to see how their accounts to health professionals may change or alter over time and how one consultation experience may inform a subsequent one.

Finally, there needs to be more evaluative research that examines the quality of communication in consultation involving professional and lay interpreters. In this study, I have touched upon some issues that are introduced into the consultation by an interpreter. Often, it is assumed that professional interpreters are trained to reliably translate information however, as this study has shown, this might not always be the case. These issues need to be further teased out in a study involving more observations of triadic consultations. Although, I did not draw out any differences between Pakistani-born and British-born interpreters due to the limited number of interpreters that took part in this study, I argue that differences may exist in terms of how they choose to interpret and may have implications for training to professional interpreters.

## **10.18 Conclusion**

In this thesis, I have illustrated by using a multi-method case study approach, how the diabetes consultation between Pakistani patients and their health professionals is complex and can be problematic. As well as a language difference between patients and providers, there are many other barriers that affect the quality of communication between them. Communication can potentially be improved by addressing some of the barriers that both patients and providers experience in the consultation. However, these barriers are interwoven and inter-connected with each other hence the problems in these consultations cannot be addressed by tackling individual barriers in isolation but by dealing with these problems together. Interpreters did not always improve communication. This thesis takes forward the argument that the consultation needs to be paid more attention because it is an important, and consistently delivered aspect of a patients' care, but thus far it seems to be an area which appears to be neglected in key policy documents. The existing diabetes consultation needs to be considered as one of the main building blocks towards establishing an effective care plan for patients with T2DM. Future research and related policy recommendations need to re-focus and further improve communication in these consultations to help Pakistani and other patients to better manage their condition.



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## APPENDICES

### Appendix 1a - Interview Schedule for Patients interview before consultation

1. How did you come to find out you had diabetes?
2. How long ago was this?
3. Why do you think you got diabetes?
4. How do you manage your diabetes? Diet/pills/insulin
  - Do you manage your diabetes according to advice given by health professionals, if not how do you manage it and why?
  - Do you have any concerns or problems with your diabetes and its management?
  - Are you on tablets/insulin, what are these?
  - Do you manage your diabetes by dietary changes and exercise as well as tablets and so on.
5. How do you feel you are managing your diabetes at the moment?
  - Is there anything you feel you can do better manage it?
  - Is there anything you feel the healthcare professionals can help you with?
  - Do you have any concerns or worries about your condition?
6. Who in the health services do you see?
7. How often do you have appointments?
  - Which appointments do you find the most useful and which do you not?
  - Which health professionals do you prefer to see and why?
8. How easy is it for you to ask questions in these appointments?
9. Who is your next appointment with?
  - What do you hope to get out of your next appointment?
  - Why do you think this appointment has been arranged?
  - Do you and your healthcare professional usually agree on the decisions that are made?
10. Have you already seen the health professional you are due to see?
11. Will you be asking the healthcare professional about any other problem while you are there?
14. What will happen in this appointment?
  - Probe for Expectations like advice, information, tests, investigations etc...
  - How long does this appointment usually last
  - Do you find these appointments useful?
15. Will you be raising any of your concerns about your diabetes if so, what do you expect the health professional to do/say?
16. Do you attend all your appointments, if so why and if not why not?
17. How do you think doctors expect you to be in the consultation is?

18. How do you think the consultation could be improved to better meet the needs of Pakistani People?

19. Do you have any preferences to where you are seen and why?

20. What do you think are the least and the most important things in the consultation?

- Did you find anything helpful/unhelpful?

21. What do you expect from diabetes health services in general?

22. Will you be taking an interpreter with you (family member or professional?)

-If family-

- how easy is it for you to arrange for someone to go with you

-Any problems or issues with regards to taking a family member

If professional interpreter

- How easy/ difficult is it to arrange for a professional interpreter and is there a difference in availability depending on whether you are going to the hospital or your GP.
- Do you have any concerns/issues about professional interpreters being present?

23. Does having an interpreter help in communicating with the health professional.

- If no interpreter, how well do you think you communicate with the health professional
- Has the H/P ever requested for you to bring an interpreter?
- Do you think you would benefit if you had an interpreter?

24. Have you had any experiences of diabetes services in Pakistan?

- How do health services over there compare with here?
- Do you have appointments there?
- How do health professionals compare with over here, how do they treat you?
- If you lived in Pakistan how do you think you would use the health services there for treatment and management of your diabetes?

25. Is there anything you want to add? What do you think are the most important things we've talked about today?

## **Appendix 1b - Interview Schedule for Patients interview after consultation**

Many questions asked were based around what happened in the consultation. The initial set of questions I asked were more generic and then I ask more specific questions about what went on in the consultation.

1. How do you feel the consultation went?
2. Do you think you understood everything the healthcare professional told you?

Was there anything that could have been made clearer?

Were you confused by anything that was said?

3. Did you agree with everything they said?
4. Was there anything that you would have liked to discuss but didn't?
5. Do you feel your concerns have been addressed?

If not why do you feel this was?

6. Was there anything that you would have liked to discuss but didn't?

If so what issue and why they didn't you bring it up?

7. Do you feel the consultation was helpful, if so how?

If it wasn't helpful then why not?

8. Did you expect the consultation to be the way it was?

Did anything different happen at this consultation, what and why do you think this is?

9. Is there anything you would like to have happened differently in the consultation?
10. What did you feel about the amount of time the healthcare professional spent with you?
11. Do you think your appointment would be any different if the healthcare professional was?

Pakistani

The same gender as you

12. What things do you think make communication with the healthcare professional easier/difficult?

13. Is there anything more you would have like to have happened in the consultation?

14. Did you understand for what purpose the healthcare professional carried out physical examinations?

15. Does the advice they give in terms of lifestyle changes make sense to you in light of your culture and religion?

16. Did you feel the healthcare professional made an effort to understand your condition/management regimen in light of your beliefs?

17. What was agreed in the consultation?

18. What actions are you required to take?

19. Will you take these actions?

If not why not?

20. What did you think the most important things were in the consultation in terms of what was said or physical examinations that were carried out?  
Least important things?

**Specific questions based on the events of the consultation** – The following question examples are taken from the interview schedule I used for Mr Raza (see chapter eight) who consulted with a DSN. Mr Raza also saw a dietitian but I have not included these questions in this appendix as it was not the consultation I chose to discuss in chapter eight.

1. Did you expect to be told whether to go on insulin or did you expect the nurse to take a test and tell you later on?
2. How do you feel about possibly going onto insulin?
3. you mentioned you had not been successful in controlling your diabetes through exercise and diet, what did you mean by that  
(Remind him of his comment during the consultation that his medication for gout raised his blood sugar readings)
4. You didn't take the list of medications with you, do you usually?
5. The nurse mentioned that there were two reasons why the BG readings would go high one cause of the pain and the other due to the medication what do you make of this.
6. What exercise do you do?
7. Why did you want to see the dietitian if you felt that your diet was going good.
8. What did you feel about her advising you to do more exercise?
9. What would you describe the differences between these consultations with the nurse/ dietitian and the consultant to be?
10. Which would you regard to be the most important consultations?
11. How are your readings in the early morning now, why did you not record them in your diary?
12. Have you adjusted the tablets in accordance with the advice the nurse gave you?
13. Why did you not write the low readings down? 1 Avandia and 2 Metformin and the nurse suggested missing out the avandia and only metformin
14. What did you make of her advice that you would have to break fast if your sugar levels are low? Like if you checked it and it was 2 or3 would you then break your fast?
15. How are your eyes today? (I noticed that he kept on wiping his eyes during his pre-consultation interview and he was sat indoors).
16. Were you satisfied with the outcome of the issue you raised about your eyes?
17. You told her that you had talked to the doctor about it several times but you said the doctors are saying they are fine and you were saying that they are not, the nurse suggested that you go might want to go to the opticians, what did you make of this suggestion?
18. How about the colours of your eyes? She was possibly suggesting that you might have cataract.
19. The nurse suggested that you could ask the doctor in your next consultation appointment and what do you make of this?
20. Will you mention your eyes to the doctor in the diabetes clinic?

21. How did you feel when she said that if your BG reading was high that you would have to go on to insulin?
  22. How do you feel the interpreter affected the consultation?
  23. How did you feel she translated?
  24. Could you understand some of the things the health professional was talking about in English?
- What did you understand?
25. Do you approach this interpreter outside the consultation?

## Appendix 1c - Interview Schedule for Health Professionals

Many questions asked were based around what happened in the consultation. The initial set of questions I asked were more generic and then I asked more specific questions about what went on in the consultation. Health professional interviews were considerably shorter than the patient ones so questions which were the most relevant were selected from the following list.

1. What had you hoped to achieve in the consultation in advance of seeing the patient?

2. General overview of the consultation

How do you feel it went?

Is there anything about it that you would wish to discuss?

What things do you think the patient did not understand?

3. Do you feel the patient understood everything you said to them?

How did you establish understanding

If they didn't seem to understand everything, why do you think that is

4. Did you understand everything the patient said to you?

What if anything

5. Did you discuss everything you intended to discuss with the patient?

Did the patient respond appropriately?

Do you think they took your advice/information seriously?

Do you think they will act upon the advice/information you gave them?

Did you feel the patient agreed with everything you said?

6. Did you think the patient had any concerns, if so, do you feel you were successful in addressing these concerns?

7. Is consulting with minority ethnic patients different from consulting with white patients, if so how?

8. Do you feel there were any issues arising due to the patient's competence in English?

If no interpreter present, do you think the patient or yourself would have benefited from having one present?

9. If an interpreter was present, how did you find it?

Do you feel the patient understood everything you were saying through the interpreter?

Did you feel the interpreter was relaying all of what was being said between you and the patient?



If family member interpreting, do you think that decisions or agreement was being expressed by the patient and not the family interpreter

Do you prefer a professional interpreter to a family interpreter?

10. How well do you think the patient is managing their diabetes?

If not so good, why do you think that is?

11. What are your thoughts on patients having an equal say in the consultation?

Do you feel you encourage this in your consultations?

How easy/difficult is it to involve this patient group in the consultation?

Do you think these patients wish to have a say in treatment decision making?

12. What messages do you think the patient took away from the consultation today?

13. What do you think the most important issues discussed in the consultation were?

Also the least important issues

14. Can you think of ways in which the consultation can be improved for these kinds of patients?

15. Is there anything you would like to add?

16. Do the health professionals perceived outcomes of the consultation as the patient, need to ask this explicitly to be able to compare.

17. How often do you see Pakistani patients in your clinic?

18. Are all issues that patients talk about relevant to your consultation or not?

19. Do patients usually bring their medications with them and does the hospital have a record of this?

Some specific questions that were asked to the doctor who consulted with Mr Ibrar (see chapter six).

1. You advised Mr Ibrar to increase their insulin as their HbA1c was above 8, how do you feel the patient is managing their diabetes on the whole?

2. Mr Ibrar seemed concerned about his feet and his tightened finger, how do you feel about Mr Ibrar raising these issues in his consultation?

3. How did you think Mr Ibrar's English was?

4. How did you establish that he understood what you were saying?

5. Were you aware that the patient had angina and if so would it have made any difference in what was discussed during the consultation?

6. Do you think Mr Ibrar is keeping up his exercise regimen?

## **Appendix 1d - Interview Schedule for Interpreters**

1. Have you interpreted for clients/family member/friend in the past?

What other experiences of interpreting have you had

If yes, was the consultation how you expected it to be?

2. How do you feel the consultation went?

Do you feel the purpose of the consultation was achieved?

3. Did you feel you were heavily involved in the consultation?

If so how?

If not why not?

4. Do you feel the patient could understand some English?

5. Do you feel you interpreted everything that was said accurately?

If so, how easy was it do so

If not, why not

6. Did you find some things that were said more difficult to interpret than other things?

If so why (probe for cultural differences)

7. Did you feel the need to say anymore than just interpreting what was said between the patient and the Health professional?

8. Do you feel the patient relied on you in other ways?

If so, how? (support, advocate)

9. Do you feel the patient and health professional understood everything that you interpreted?

Depending on what happened in the consultation ask for reasons why they seemed to simplify/change/edit information.

10. Do you think the patient voiced all their concerns to the healthcare professional?

11. What do you think the most important issues discussed in the consultation were?

Also the least important issues

12. Is it easier/difficult to interpret for someone you know or not?

13. Is it easier/difficult to interpret for someone who is a different gender to yourself?
14. Do you feel the patient and the healthcare professional were satisfied with the outcome of the consultation?
15. What do you think the most important issues discussed in the consultation were?  
Also the least important issues
16. Can you think of ways in which the consultation can be improved for these kinds of patients?
17. How would you prefer patients to be when you are interpreting for them?
18. Can you describe to me incidents where interpreting was made difficult for you?
19. Do you ever bring your personal experience or experience of others that you know to assist in making the patient understand?
20. This patient didn't bring their medication with them is this often the case and how easy or difficult is it to discuss medication without the information?
21. Do you ever write information down for patients in English or in Urdu?
22. Probe about patient's religious and cultural beliefs? Do you relay this information and how easy/difficult to do so like certain dietary beliefs.
23. What makes you different from say a family member interpreting?
24. I remember seeing you with your mother in law the other day did you interpret differently in light of having personal knowledge about this patient?
25. Advocacy, support inside and outside of the consultation.
26. Is gender ever an issue for either you or the patient?
27. Do you have any recommendations?
28. Why would you say that our people are not managing their diabetes as well?
29. Do you feel that other interpreters interpret the way you do?
- 30 Do you think there may be a difference in the style of interpreting between someone who British born or Pakistani born.

## **Appendix 2a - Patient Invitation Letter**

(Also translated in Urdu)

### **Diabetes consultations with Patients of a Pakistani heritage**

Dear

I am writing to ask if you would be willing to take part in the above study which is being carried out at Edinburgh University.

Type 2 diabetes is a growing health problem amongst people of a Pakistani heritage who live in Scotland and efforts are currently being made to make diabetes services more culturally sensitive. To do this, researchers would like to look at how healthcare professionals are communicating with their patients in diabetes consultations so that recommendations can be provided on how the delivery of information and health care may be improved. Your name has been identified by name search, however if you are not of Pakistani heritage then please accept our apologies for any inconvenience and disregard this letter.

If you choose to take part in the study, you will be interviewed twice, once before and once after your appointment in a language of your choice and in your own home (unless you would prefer to be interviewed elsewhere). In addition, the researcher will ask your permission to sit in on your appointment with myself to listen to what is said. The researcher will have no involvement in our discussion and her presence will have no bearing on your treatment. If you bring someone along to interpret for you, the researcher would like to interview them too.

The research is funded by the Scottish Government and enclosed is an information sheet about the study for you to take a look at. If you have any questions about the study, please do not hesitate to contact Naureen Ahmad 0131 651 1157, who will be doing the interviews and who speaks Punjabi, Urdu and English.

If you are interested in taking part, I would be very grateful if you would complete the enclosed form and return to Naureen Ahmad (in the pre paid envelope). If you do not wish to take part, then please excuse me for contacting you.

Thank you very much for reading this letter.

With kind regards

## **Appendix 2b - Patient Information sheet**

### **Diabetes appointments with patients of a Pakistani heritage in Lothian**

I would like to invite you to take part in a research study exploring patients' experiences and views of diabetes consultations (appointments) with their healthcare professionals. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it will require of you. Please take the time to read the following information and discuss it with others if you wish. If you have any questions, please do not hesitate to contact Naureen Ahmad 0131 651 1157, in your preferred language (English, Urdu or Punjabi).

#### **Why is this study being done?**

Type 2 diabetes is a growing health problem amongst Pakistanis who live in Scotland and efforts are currently being made to make diabetes services more culturally sensitive. To do this I need to look at how healthcare professionals are communicating with their patients in diabetes consultations so I can provide recommendations for ways in which the delivery of information and health care can be improved. Hence, this study will involve patients of a Pakistani heritage with type 2 diabetes, the healthcare professionals with whom they have their consultation and –if they are used- the people who come along to interpret. I hope that you are willing to help, so that I can learn about those things that make communication difficult or easy in consultations with your healthcare professionals.

#### **Why have I been chosen?**

You have been invited to take part because you have type 2 diabetes and attend consultations at your doctor's surgery/hospital. I am going to interview 16 patients for this study. I will also interview their healthcare professionals and interpreters (if used).

#### **What is involved?**

If you are willing to help me I would like to:

- Interview you before your consultation
- To sit and observe your consultation, and
- Interview you one last time after the consultation

Ask for your permission to approach and involve the healthcare professional you are due to see about your diabetes at your doctor's surgery.

Ask for your permission to approach and involve the person who will be interpreting for you, if you use such a person.

The first interview would take place about two weeks before your consultation and the last interview about a week after the consultation. You can choose the time and place of your interviews. It is estimated that each interview will last about one hour, although this will

depend on how much you wish to say. I can interview you in Punjabi, Urdu or English. During your consultation I will sit quietly in the room and have no involvement in your conversation with your healthcare professional.

I will also be interviewing your healthcare professional and your interpreter (if you have one) after the consultation.

**Do I have to take part?**

It is entirely up to you whether you take part in this study. If you do not want to take part, or you decide to withdraw at any time, your medical care will not be affected in any way.

**Your rights**

If you decide to take part, you will be asked to sign the consent form either before the first interview or at the time of the first interview. You will be given a copy of this form to keep. All information you give as part of this study will be strictly confidential.

Thank you very much for your time and help.

Naureen Ahmad

## **Appendix 3a - Health Professional Invitation Letter for use in General Practice/Community Recruitment<sup>7</sup>**

Dear Dr [name]

A qualitative exploration of cultural and language barriers in diabetes consultations involving patients of a Pakistani heritage in Lothian

I am writing to ask if you would be willing to take part in the above study which is being carried out at the University of Edinburgh. Type 2 diabetes is a growing health problem, particularly amongst Pakistani people living in the UK and various studies have shown that Pakistani patients find it difficult to manage their disease. These difficulties may be due, in part, to their having poor diabetes knowledge and awareness. It has been suggested that language and cultural differences present challenges to effective communication in diabetes consultations. Therefore, the purpose of this research is to investigate diabetes consultations with Pakistani patients and their healthcare professionals in order to determine ways in which the delivery of information and advice can be improved for future patients.

I am approaching you to take part in this study as one of your Pakistani patients with type 2 diabetes has already expressed a willingness to take part and for one of their diabetes consultations with you to be observed. Her consultation with you is on the morning of Thursday 19<sup>th</sup> October.

If you agree to take part, I would like to observe this consultation between you and this Pakistani patient and to interview you briefly afterwards. I have enclosed an information sheet for you to take a look at and will attempt to contact you by phone sometime soon to confirm whether you may take part or not.

The research is funded by the Health department Scottish Executive and will be carried out in Lothian. If you have any queries about the study, please do not hesitate to contact Naureen Ahmad 0131 651 1157.

Thank you for reading this letter

With kind regards

Yours sincerely,

Naureen Ahmad

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<sup>7</sup> This letter was modified for use in hospital recruitment.

## **Appendix 3b - Health Professional Information Sheet for use in General Practice<sup>8</sup>**

### **A qualitative exploration of cultural and language barriers in diabetes consultations involving Pakistani patients in Lothian**

I would like to invite you to take part in research exploring barriers and facilitators to effective communication between Pakistani patients with type 2 diabetes and their healthcare professionals. Please take the time to read the following information and discuss with others if you wish. If you have any questions please do not hesitate to contact Naureen Ahmad 0131 651 1157.

#### **Why is this study being done?**

The study is funded by the Scottish Executive health department and will be carried out in Lothian. Type 2 diabetes is a growing health problem, particularly amongst Pakistani people living in the UK. Pakistani patients with type 2 diabetes have poorer management than white patients. This is partly due to them having poor diabetes knowledge and awareness. This study will investigate the main tool used by healthcare professionals to provide diabetes education/information and make decisions about treatment: the consultation. As part of the research, I will be sitting in on and observing diabetes consultations involving healthcare professionals and Pakistani patients. I will be compiling 16 case studies involving 16 patients, their healthcare professionals and interpreters (if present). Patients will be interviewed in the language of their choice before and after the consultation. Healthcare professionals and interpreters (if present) will be interviewed once after the consultation.

#### **Why have I been chosen?**

One of your Pakistani patients with type 2 diabetes has consented to take part in the study and for me to observe one of their diabetes consultations with you.

#### **What is involved?**

I hope that you will be willing to help me and take part. If you agree to take part I will observe a consultation involving yourself, your Pakistani patient and his/her interpreter (if such a person is used). I would also carry out a brief interview with you after the consultation to ask about your views about the consultation and its outcome. The interview would take between 10 and 20 minutes of your time, depending on how much you wish to say. There is also the option to be interviewed by telephone at a time convenient to you. Hence, your involvement will not be too time-consuming.

#### **Your rights**

If you decide to take part, you will be asked to sign the consent form before the consultation. You will be given a copy of this form for your records. All information will be kept strictly confidential.

Your co-operation will be much appreciated

Thank you very much for your time and help

Naureen Ahmad

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<sup>8</sup> This information sheet was modified for use in hospital recruitment.



## Appendix 4a - Professional Interpreter Invitation Letter<sup>9</sup>

Dear [interpreter's name]

Diabetes consultations with Pakistani patients

I am writing to ask if you would be willing to take part in the above study which is being carried out at the University of Edinburgh. Type 2 diabetes is a growing problem. Efforts are currently being made to improve the delivery of culturally sensitive services for Pakistani patients with type 2 diabetes. As part of this we want to look at diabetes consultations involving Pakistani patients, their healthcare professionals and interpreters in order to determine ways in which services can be improved. I am approaching you because your client has already expressed an interest in taking part in the study and has indicated that she/he will be asking you to come along and interpret at their next diabetes consultation.

If you are willing to take part, I would like to observe the consultation between the patient, their healthcare professional and you as the interpreter and to interview you briefly afterwards. I have enclosed an information sheet for you to take a look at together with a form you can complete if you would be interested in discussing the study further and hopefully taking part.

The research is funded by the Scottish Executive Health Department and will be carried out in Lothian. If you have any queries about the study, please do not hesitate to contact Naureen Ahmad 0131 651 1157.

Thank you for reading this letter

With kind regards

Your sincerely,

Naureen Ahmad

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<sup>9</sup> This letter was adapted for use with lay interpreters.

## **Appendix 4b - Professional Interpreter Information Sheet<sup>10</sup>**

### **Diabetes consultations with Pakistani patients**

I would like to invite you to take part in a research study looking at diabetes consultations (appointments) involving Pakistani patients and the role of interpreters in these consultations. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it will require of you. Please take the time to read the following information and discuss it with others if you wish. If you have any questions please do not hesitate to contact myself Naureen Ahmad 0131 651 1157.

### **Why is this study being done?**

Type 2 diabetes is a growing health problem amongst Pakistanis who live in Scotland and efforts are currently being made to make diabetes services more culturally sensitive. To do this I need to look at how healthcare professionals are communicating with their Pakistani patients in diabetes consultations so we can suggest ways in which services can be improved. As many Pakistani patients take someone along to their consultation to interpret for them, it is very important that interpreters are included in the research. The research involves me sitting in on and observing diabetes consultations involving healthcare professionals, Pakistani patients and their interpreters and talking to people about their experiences afterwards. It will be possible for me to understand what is being said in the consultation as I speak and understand Punjabi and Urdu as well as English.

### **Why have I been chosen?**

One of your Pakistani clients has agreed to take part in the study and has indicated that you will be coming along to their next diabetes consultation to interpret for them

### **What is involved?**

If you agree to take part I will observe a consultation involving yourself, your client with diabetes and their healthcare professional. I also hope to carry out a brief interview with you after the consultation, so you can talk about your experiences of acting as an interpreter. The interview will take between 10 and 30 minutes depending on how much you wish to say. There is also the option to be interviewed by telephone at a time convenient to you. Hence, your involvement will not be too time-consuming.

### **Your rights**

If you decide to take part, you will be asked to sign the consent form before the consultation is due. You will be given a copy of this form for your records. All information will be kept strictly confidential.

Your co-operation will be much appreciated

Thank you very much for your time and help

Naureen Ahmad

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<sup>10</sup> This information sheet was adapted for use with lay interpreters.

## Appendix 5 – Patient Consent Form<sup>11</sup>

### CONSENT FORM

Name of Researcher: \_\_\_\_\_

Please initial box

1. I confirm that I have read and understand the information sheet dated .....  
(version .....) for the above study and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time,  
without giving any reason, without my medical care or legal rights being affected.

☐

3. I agree to take part in the above study.

☐

4. I agree to the consultation being tape recorded

☐

\_\_\_\_\_  
Name of Patient

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

1 for patient; 1 for researcher.

<sup>11</sup> This consent form was modified for use with health professionals and interpreters.

## Appendix 6 - Patient opt in form<sup>12</sup>

### Diabetes consultations with Pakistani patients in Lothian

I am interested in taking part in this study and am willing to be contacted by the researcher

My preferred spoken language is: (please tick)

Punjabi

Urdu

English

Signature: .....

Please note that signing this form does not commit you to taking part in this research

Name (please print):

.....

Date of birth: .....

Address (please print):

.....

.....

.....

Postcode: .....

Telephone number: .....

Please return this form to the researcher in the pre-paid envelope provided

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<sup>12</sup> Separate opt-in forms were created for health professionals and interpreters.